



Empirical and Normative Implications of Social Networks for Disparities: The Case of Renal Transplantation

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Empirical and Normative Implications of Social Networks for Health Disparities: The Case of Renal Transplantation

A dissertation presented

by

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to

The Department of Health Policy

in partial fulfillment of the requirements
for the degree of
Doctor of Philosophy
in the subject of

Health Policy

Harvard University

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*Empirical and Normative Implications of Social Networks for Disparities: The Case of
Renal Transplantation*

Abstract

This dissertation examines the extent to which individual-level and social network-level factors explain disparities in living donor kidney transplantation (LDKT) and considers the moral implications.

Paper One examines whether patient characteristics explain racial disparities in the rate of donor presentation and LDKT in a sample of 752 potential kidney recipients and 654 potential kidney donors. Propensity score matching and subclassification were used to balance the patient characteristics. Survival models revealed that only 24% of blacks compared to 39% of whites would have at least one potential donor evaluated within the first year, even after accounting for differences in the distribution of patient characteristics. Thus, lower rates of donor presentation among black recipients cannot be explained by differences in individual-level characteristics.

Paper Two examines whether differences in social networks contribute to disparities in LDKT. Using interview and medical record data from a representative sample of 389 dialysis patients in Greater Boston and a subsample of 302 alters, we found that social network characteristics, especially network size, were strongly predictive of pursuing LDKT. Significant racial disparities in health and medical distrust among social networks of black patients present compelling evidence for network effects. Fewer network members of black

patients may be eligible for donation owing to compositional health differences, and those eligible may be less willing to donate due to greater distrust or poor socioeconomic position.

Paper Three argues that society ought to be concerned with previously neglected disparities in LDKT, specifically the fraction stemming from disparities in social networks because networks provide one pathway by which inequalities can be perpetuated throughout society and over time. Insofar as social networks are influenced by an unjust distribution of social forces, and social networks influence life chances by restricting (or enhancing) one's ability to obtain a LDKT, then life chances of dialysis patients are unjustly determined by social networks. Potential policies aimed at providing compensatory damages to patients whose networks have been adversely affected by the unjust influence of social determinants are examined.

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Writing a dissertation is a lonely process, but I was lucky to have been surrounded by smart, funny, and inspiring friends who always gave me a hand when I needed it. My cohort was an amazing source of support – our doubling time must have set a record among Harvard doctoral programs. Adriane Gelpi and Brendan Saloner, without whom I would have been lost in the ethics track and maybe in life as well. I already miss our drinks at the Cellar. Ricky Gonzales has been a great teacher, dog sitter, and friend throughout my time at Harvard. Lula and I have much to thank him for. I relied upon Tisa Sherry, Candice Player, Paula Chu, Sae Takada, and many others for humor and morale throughout this journey. Yves Chretien was a wonderful and cheerful friend and collaborator. Finally, to the many students who worked with me, Helen Yu, Nicole St Omer-Roy, Michelle Seslar, Jackie Hsieh, Rick McKellar, Alexis Karlin, Joey Lopez, Rui Wang, and especially Erica Langnas, I am eternally grateful for their hard work and for helping me start my first lab. Without them, I could not have experienced the true joys of academic life.

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Writing a dissertation is a lonely and long process, even for those who do not endure it alone. One can easily forget how hard it is to even know where to start. For my dearest Danny, who at the ripe age of 22 months, has taught me more about life, hard work, and humanity than anyone else, I am truly blessed. Above all else, I am grateful for Danny, who has bestowed upon me the most important title I have received thus far, Ima. Some say that having a child during your doctoral studies is not ideal. I would beg to differ. Danny has shown me, each day, that any large achievement begins with a small step. He has proved to me that walking really does start with rolling over, then crawling and finally pushing one foot in front of the other. Danny has taught me that walking involves pulling yourself up even after a fall, maintaining a sense of wonder, and motivating yourself and others around you to be present in the moment and to engage fully in your goal. Every big accomplishment starts with a tiny step, I thank Danny for reminding me of this daily.

Dedication

To my parents who made this possible,

To my siblings – my strongest and most enduring allies,

*To my grandparents, whose integrity, perseverance, and kindness
in the face of grave injustice
has inspired me and given me the strength*

*And to Scott and Danny,
Light of my life
who, each day, preserve my student status and make the hard work worthwhile*

“We also believe that we have a larger responsibility to one another as Americans – that America is a place – that America is the place – where you can make it if you try. That no matter how much money you start with or where you come from or who your parents are, opportunity is yours if you're willing to reach for it and work for it. It's the idea that while there are few guarantees in life, you should be able to count on a job that pays the bills; health care for when you need it; a pension for when you retire; an education for your children that will allow them to fulfill their God-given potential. That's the America we believe in. That's the America I know.”

—BARACK OBAMA, speech, May 6, 2008

Overview of the Dissertation

Rationing, discrimination, and kidney allocation: Lessons for the health care system

Nearly 85,000 people are waitlisted for a kidney transplant in the United States, with the median waiting time exceeding three years (Leichtman et al., 2008). A growing epidemic, kidney disease is the ninth leading cause of death in the United States, affecting nearly 12% of Americans over the age of twenty ("USRDS 2009 Annual Data Report. United States Renal Data System Web site."; Xu, Kochanek, Murphy, Tejada-Vera, & Statistics, 2010)¹. Medicare spending on end-stage renal disease (ESRD) rose 13.2% to \$26.8 billion in 2008, a large increase relative to 10.8% increase in overall Medicare spending. Spending on ESRD now comprises 6.6% of the total Medicare budget (excluding Part D). Despite increasing numbers of patients awaiting transplantation, only 16,829 transplants were performed in the United States in 2009, during which time 33,671 patients were added to the waiting list (OPTN, 2010). The rate of deceased donor kidney donation remains at approximately 9,000 per annum despite persistent public education and legislative adjustments to facilitate the organ-donation process. Though demand for kidneys has increased annually, the supply of deceased donors has declined since 2008 exacerbating the shortage and the need for

¹ There are two options for patients pursuing transplantation: living-donor transplantation, where a living donor donates an organ for transplantation to a patient, or deceased-donor transplantation. Both require an evaluation to test whether the patient can withstand the surgery and anti-rejection medications, and post-operative adjustment. If a patient is considered eligible following the extensive evaluation process, she is strongly encouraged to try and find a donor among family members (most likely to match) and other social network members. LDKT is associated with superior graft and patient survival rates and is more cost-effective than long-term dialysis with cross-over occurring approximately after three years (Whiting et al., 2004). Patient survival after kidney transplantation is 95%, 91%, and 85% at 1, 3, and 5 years, respectively, and higher in patients undergoing LDKT and pre-emptive (i.e., prior to dialysis) transplantation (Whiting et al., 2004). The patient is listed on the deceased-donor waiting list while potential donors are being evaluated, or in the case that no suitable donor is identified. This list is administered by the OPTN, run by UNOS, which maintains a centralized database of patients waiting for a transplant.

rationing (A. Klein et al., 2010). Though domestically, health care is implicitly rationed based on price and availability, kidney transplantation presents a rare and salient example of explicit rationing of life-saving treatment.

The wait for a deceased donor kidney, once measured in weeks and months, is now measured in years and, inevitably, will soon approach a decade or more. With the projected number of potential brain-dead organ donors ranging between 10,500 and 13,800 annually, supply cannot meet the rapidly rising demand even with improved conversion rates (USRDS, 2010). Recent growth in kidney transplantation has been largely due to more live donor kidney transplantations (LDKTs), which now account nearly 40 percent of transplants taking place in the U.S. (Lentine et al., 2010). LDKT presents an increasingly compelling approach to the problem of organ scarcity (Sheehy et al., 2003). LDKT is considered the optimal treatment for ESRD, conferring improved longevity and quality of life at significant cost-benefit to the healthcare system relative to dialysis or deceased donor transplantation (Whiting et al., 2004)

Resource allocation in transplantation may serve as an example for other areas of health care, in that it has established a federal process to explicitly ration based on well-defined criteria, and has generally been accepted by the American public. Though rationing of health care has largely been obscured in policy debates by expanding supply through the continued increase in federal and private spending, this strategy is unsustainable and has resulted in skyrocketing health care costs over the past half-century (Roehr, 2010). Despite the negative public response to perceived rationing in the *Patient Protection and Affordable Care Act*, Americans have come to terms with rationing in the context of kidney transplantation.

Public resources and public trust are essential to the function and sustainability of an organ sharing network, because first, ESRD patients must be willing to be evaluated and waitlisted for life-saving treatment using common metrics without trying to procure organs from alternate sources (e.g. the black market), and second, donors must believe that organs donated into the system will be distributed fairly. In addition, organs donated from altruistic living-donors (i.e. non-directed donors) or deceased donors are entrusted into a public pool and therefore are public resources. Fairness, predictability, and transparency are critical to ensuring continued public participation. The deliberative process of setting the algorithm for kidney allocation illustrates some important lessons for the broader health care system. Namely, it demonstrates that the public can support rationing of treatment, provided that the process is transparent, iterative, and enhances equity and efficiency.

Contrary to optimistic claims that universal coverage (attempted through Medicaid expansions, insurance exchanges and the individual mandate) will mitigate health disparities, the transplantation case demonstrates that, in spite of a fully insured market, legislation requiring equity, and research aimed at mitigating disparities, disparities persist.(K Ladin, Rodrigue, & Hanto, 2009) Furthermore, transplantation affords a unique opportunity to examine how to fairly ration health care while maintaining a commitment to mitigating disparities. The transplantation case study illuminates mechanisms underlying disparities while avoiding some of the deeply entrenched problems of health services research, namely that mechanisms often cannot be disentangled due to endogeneity (i.e. insurance and socioeconomic status (SES), politicization of rationing, etc.). Applying innovative methodological approaches to separately investigate the contribution of supply and demand

mechanisms, we can better understand how to design successful interventions and policies aimed at alleviating disparities and enhancing equity.

The Institute of Medicine defines disparities as an unfair treatment of patients on the basis of irrelevant traits, such as race or ethnicity (Smedley, Stith, & Nelson, 2003). Thus far, the disparities literature has largely focused on explaining health disparities by focusing on the role of individual-characteristics (e.g. socioeconomic status, race, etc). (Alexander & Sehgal, 1998; Epstein et al., 2000; Siminoff, Burant, & Ibrahim, 2006; Smedley, Stith, & Nelson, 2003) While researchers have successfully identified individual-level ‘risk factors’, such as race/ethnicity, income, education, gender, and age, amongst many others, these individual-level factors have been inadequate in accounting for observable gaps in health or health care.

Paper One examines whether patient characteristics (demand-side factors) explain racial disparities in the rate of donor presentation and live donor kidney transplantation (LDKT). Although the National Organ Transplant Act calls for equity in access to transplantation, scarcity and racial disparities persist. Examining 752 potential kidney recipients and 654 potential kidney donors, we compared whether the gap in time until first potential donor presentation and transplantation was due to differences in baseline characteristics between blacks and whites. One year following patient evaluation, 45% of white and 26% of Black patients had at least one potential donor evaluated, and 16% of white versus 4% of Black recipients had received LDKT ($p < 0.001$). After projecting the distribution of covariates of white patients onto blacks and vice versa using propensity scores and subclassification, survival models revealed that disparities in time to first donor persisted. Among Blacks, the model estimated that 24% would receive at least a single potential donor within 1 year. However, when black recipients' characteristics were projected onto hypothetical white

patients, the model predicted that 39% would receive a donor within 1 year. Lower rates of donor presentation for black recipients cannot be explained by differences in individual-level (demand) characteristics. Instead, future research should explore differences in supply, namely on the role of social networks.

Paper Two examines whether supply-side explanations, namely differences in social networks, account for disparities in donor presentation or willingness of potential donors to pursue LDKT. Although Blacks constitute 37% of the United States population receiving dialysis and 35% of those on the transplant waiting list, they receive just 13% of live-donor transplants.(Norris & Agodoa, 2005) Social networks have been shown to confer risk of numerous health conditions and health behaviors, including precursors to chronic kidney disease (CKD) (e.g. obesity). Odds of finding eligible donors depend on the health, financial status, willingness to undergo donation, and number of persons in social network (representing pool of potential donors). We hypothesize that networks of Black recipients might restrict the likelihood of LDKT in two ways: (1) limiting the number of eligible donors due to a higher proportion with medical contra-indications to donation and socioeconomic status, (2) limiting the number of willing donors due to mistrust of the health care system. We interviewed and reviewed medical records from a representative sample of 389 dialysis patients in the Greater Boston area (oversampling Blacks) and a subsample of 302 alters about the role of social networks in their decision-making surrounding transplantation. Consistent with our previous findings, individual-level patient characteristics such as socioeconomic status, willingness to pursue transplantation, compliance, health status, or trust in the medical system, do not explain racial disparities. Instead, we find significant disparities in social network characteristics; particularly trust in

the medical system and health status, potentially explaining the gap in LDKT between Blacks and Whites. Compositional differences in the health of social networks of Black patients suggest that fewer network members may be eligible for LDKT, and those who are eligible, may face more systemic barriers owing to poor socioeconomic position.

The government and healthcare institutions ultimately bear responsibility for preserving equality and life chances for all patients with ESRD. Despite being one of the only conditions fully insured by Medicare before age 65, disparities persist, illustrating the limited role of universal coverage. While the deceased-donor algorithm has been amended to improve fairness and mitigate racial disparities, increasing scarcity of deceased-donor organs is leading more patients to turn to LDKT as their only option. Thus far, organ allocation algorithms have only taken into account deceased-donor organs, neglecting the increasing role of living-donor organs in addressing organ scarcity. From an economic perspective, deceased and living donor organs are perfect substitutes, collectively embodying the total pool of available organs where each recipient who receives a living-donor transplant reduces the need for a corresponding deceased-donor organ. Excluding living donor kidneys from allocation algorithms is tantamount to neglecting 40 percent of the potential organ supply from communal distribution and rules of fairness governing the rest of the organ supply. Given that the market for organs is finite, and living-donor organs serve as a substitute for deceased-donor organs, disparities in LDKT continue to undermine equity in the kidney allocation system by contributing to an inequitable distribution of organs.

Paper Three examines whether society ought to be concerned with disparities in transplantation as availability of transplants is an intermediary step to addressing broader

health disparities. In particular, this paper argues that society ought to be concerned with previously neglected disparities in LDKT, specifically the fraction stemming from disparities in social networks because networks provide one pathway by which inequalities can be perpetuated throughout society and over time. The paper first demonstrates that numerous theories of distributive justice converge in suggesting that variation in health outcomes stemming from social forces are ethically problematic. It then illustrates that disparities in LDKT present a cause for concern since they are, in some part, caused by unjust social forces and further exacerbate inequality among vulnerable populations. Insofar as social networks are influenced by an unjust distribution of social forces, and social networks influence life chances by limiting or enhancing a patient's ability to obtain a LDKT, then life chances of dialysis patients are influenced by an unjust distribution of social forces via a social network mechanism. Thus, patients with networks who have been impoverished by an unfair distribution of social determinants in ways that would make them less likely or able to donate are entitled to compensation. Finally, this paper explores potential policies aimed at providing compensatory damages to patients whose networks have been adversely affected by the unjust influence of social determinants.

Chapter 1

Do Recipient Factors Explain Racial Disparities in Living Donor Presentation and Kidney Transplantation?

1.1 Introduction

Although demand for kidneys has increased annually, the supply of deceased-donor organs has not kept pace. The median waiting time is over three years, exacerbating waiting-list mortality and the need for rationing.(A. Klein et al., 2010) Recent growth in kidney transplantation has largely been due to an increase in living donor kidney transplantation (LDKT), which accounts for 40% of kidney transplants in the U.S.("Organ Procurement and Transplant Network database") LDKT is the most cost-effective treatment for ESRD and provides improved survival and quality of life.(Lentine et al., 2010; Liem, Bosch, Arends, Heijenbrok-Kal, & Hunink, 2007; Whiting et al., 2004; Wolfe et al., 1999) Despite these benefits as well as universal coverage of transplantation and emphasis on equity in transplantation, LDKT has been unevenly experienced by racial minorities.(Eckhoff et al., 2007; K. Ladin & Hanto, 2010) In 2008, although blacks comprised 30% to 40% of the dialysis population, waiting list, and deceased-donor recipients, they received only 13.4% of LDKTs and have failed to benefit from the increase in LDKTs seen overall. (U.S.

Department of Health and Human Services, Resources and Services Administration, & Bureau, 2009; USRDS, 2010)

Underlying determinants of racial disparities in renal transplantation remain incompletely understood.(K. Ladin & Hanto, 2010) Prior studies have largely focused on recipient or “demand-side” factors including: race, gender, age, financial status, cultural beliefs, co-morbidities, insurance status, unemployment, patient preferences, incomplete transplantation evaluation, and bias in physician decision-making, particularly when evaluating patients of low SES, low literacy rates, older age, and minorities.(Ayanian et al., 2004; Ayanian, Cleary, Weissman, & Epstein, 1999a; Eckhoff et al., 2007; Epstein et al., 2000; A. S. Goldfarb-Rumyantzev et al., 2006; Gore, Danovitch, Litwin, Pham, & Singer, 2009; Lentine et al., 2010) These studies have made two assumptions: first, that disparities in LDKT are a function of recipient characteristics; and second, that these characteristics influence white and black patients equally. Multivariate regression models used to account for baseline differences between blacks and whites implicitly assume that the effect of included covariates is comparable for blacks and whites.(Chandra & Staiger, 2010) This assumption can lead to insufficient accounting for confounders and misspecified models because the effect of covariates varies significantly by race, biasing estimates from a combined model.(Jha, Staiger, Lucas, & Chandra, 2007) For example, most models estimating racial disparities in transplantation include age and hypertension, characteristics known to differ by race (black potential recipients are often younger and more likely to be hypertensive), and whose effects may also vary by race (e.g. younger age may not be as advantageous for blacks as it is for whites).(USRDS, 2010) Prior studies have suggested that, if patient characteristics and distribution of commonly cited risk factors were similar for blacks and whites, disparities in transplantation would diminish significantly. (Ayanian et al.,

2004; Biller-Andorno, 2002; Eckhoff et al., 2007; Epstein et al., 2000; Kayler et al., 2003; Norman, Song, Hu, & Ojo, 2009; Norris & Agodoa, 2005; Reese et al., 2008; Reeves-Daniel et al., 2009; Young & Gaston, 2000) This hypothesis, however, has not yet been tested.

This paper addresses two critical questions. First, are racial disparities in LDKT rates associated with a lower rate of potential donor presentation? Second, to what extent do patient characteristics account for these disparities? We hypothesized that redistributing covariates would decrease the percentage of white patients with a potential donor evaluation and would increase the percentage of black patients with a potential donor, given previous findings attributing the racial gap to these covariates. In order to estimate the counterfactual redistribution of covariates, we used a novel statistical approach that does not assume an equal effect of covariates among blacks and whites to examine whether racial disparities persist after accounting for differences in baseline characteristics and after holding institutional characteristics constant. These statistical methods have not been applied to this question before. Given the focus on racial disparities in recent legislation, namely, the Patient Protection and Affordable Care Act (PPACA), it is imperative to accurately estimate the gap and better delineate significant risk factors to effectively intervene.

1.2 Methods

1.2.1 Study Population

Potential Recipients and Donors: The potential recipient sample included 840 consecutive patients with end stage renal disease (ESRD) on peritoneal or hemodialysis over age 18 that identified racially as black or white at the time they initiated a first-time evaluation for kidney-only transplantation at Beth Israel Deaconess Medical Center (BIDMC) between November 1, 2004 and May 1, 2009. Eighty-seven patients were excluded

from the analysis due to prior wait listing and one patient was excluded due to medical record discrepancies leaving 752 patients for further study. All patients were asked about potential living donors upon initiating their transplant evaluation. Patients with prior or preemptive (pre-dialysis) transplant evaluations were excluded because their outcomes may be influenced by previous search efforts. Potential donors were evaluated according to an established clinical pathway.(Pavlakakis & Hanto) The date of donor presentation was defined as the date of the potential donor's first evaluation note (phone interview with donor nurse coordinator). Patients and any potential donors who came forward were educated about LDKT in required classes taught by transplant nurse coordinators and were provided extensive written educational materials (available at: www.bidmc.harvard.edu/transplantcare). Recipients were then linked to their potential donors using medical records. This study was approved by the Institutional Review Board of BIDMC.

Sociodemographic and Clinical Characteristics: Data were extracted from medical records and social work notes by trained research assistants. Patient characteristics included: age (less than 50, 50-59, 60-69, and over 70), gender, race (black or white), marital status (married or unmarried), currently diabetic, presence of one or more ADL (activities of daily living) functional limitations, ABO blood type, current smoking, current drinking, current psychiatric illness (as indicated by psychiatry or social work record), current diagnosis of hypertension, dialysis type (hemo or peritoneal), BMI (less than 25, 25-29.9, 30-34.9, 35 and over), education (less than college versus college and above), employment (full-time verses less than full time or unemployed), number of living siblings (0-1, 2-3, or 3 and more), number of living children (0, 1-2, 3-4, or 4 and above). For the purposes of modeling,

these characteristics were categorized as *basic factors* (age and gender), *family factors* (marital status, number of siblings, number of children) *socioeconomic factors* (employment, and educational attainment), or *health factors* (functional limitations, ABO blood group, smoking, drinking, BMI, psychiatric history, hypertension, dialysis type).

Potential donors' characteristics included: age (by decile), gender, race (black or white), marital status (married or unmarried), and relationship to recipient (where available) were obtained from medical records, along with time from initiation of evaluation to completion of evaluation or donation status.

1.2.2 Outcomes Evaluated

Using the Kaplan-Meier survival estimator we determined the time until: (1) evaluation of first potential donor, (2) LDKT if performed, and (3) any transplantation (living or deceased donor). Recipients' time on study was censored for death (83 patients died during the study period), or reaching the end of the study period before experiencing an endpoint. For the LDKT endpoint, patients who received a deceased-donor transplant were censored at the time of transplant. Some patients became temporarily inactive on the waiting list subsequent to evaluation, meaning that for medical reasons these patients became temporarily ineligible. Patients were not censored for inactivity; these analyses estimate a patient's overall probability of having a potential donor evaluated and/or receiving a transplant during a given time period, which accounts for the possibility of entering inactive status.

1.2.3 Statistical Methods

We performed unadjusted analysis for each endpoint (discussed above) and stratified by race using the log-rank test.(Breslow, 1975) Cox proportional-hazards models were used to estimate bivariate associations between variables and endpoints.

Race-specific models were used to determine whether sociodemographic and clinical covariates affect blacks and whites differently and to infer whether the racial gap in donor presentation would remain if the distribution of covariates were reversed by race, meaning that black patients would have the distribution of sociodemographic and clinical covariates observed in white patients, and vice versa. This approach does not rely on the assumption that the effect of each covariate is uniform by race, and instead allows the effect of each covariate to vary by race. This modeling approach avoids bias stemming from a common-effects model that assumes identical effects of covariates regardless of race by superimposing a single structure on the data.(Rosenbaum & Rubin, 1983, , 1984)

We analyzed patients who had at least one potential donor evaluated within 18 months. We used this outcome because it was strongly correlated with likelihood of LDKT and best suited for the data. We used a three-step process to adjust for groups of characteristics known to influence health care disparities including: *basic factors* - age and gender ; *family factors* - marital status, number of siblings, number of children; *socioeconomic factors*- employment, and educational attainment; and *health factors* - functional limitations, ABO blood group, smoking, drinking, BMI, psychiatric history, hypertension, dialysis type (Duan, Meng, Lin, Chen, & Alegria, 2008). This approach progressively assigns white patients the distribution of characteristics of black patients, and vice versa to determine whether disparities in live donor presentation would persist under the counterfactual scenario that black recipients had characteristics of white recipients. We first used propensity scores to divide the sample into four subclasses containing white and black recipients

balanced on all covariates, yielding more reliable inference. We then fitted a Weibull regression model (J. Klein & Moeschberger, 1997) within each subclass to estimate adjusted donor presentation rates for both whites and blacks. Finally, we pooled the models' predictions across subclasses to estimate the overall adjusted rates of donor presentation. We computed all estimates and p-values using Rubin's combining rule for multiple imputation.(Rubin, 1987)

To infer whether the gap in outcomes can be attributed to measured covariates, we fitted a model using only whites, and used it to generate predictions representing the outcomes of a counterfactual population of white patients who resemble black patients on all measured characteristics. We compared the *predicted outcomes* with the *actual outcomes* for black patients, determining that remaining differences were not attributable to the covariates. We also performed this comparison in a counterfactual population of black patients who resemble white patients on all known characteristics. We grouped the predictor variables and performed the adjustment in stages to show the progressive effect of adding each additional predictor subset to the model.

We performed five imputations (separately by race) of all missing covariates values using the R statistical package MICE (van Buuren, 2007) and conducted all adjusted comparisons using standard multiple-imputation methods (Rubin, 1987). All analyses were conducted using R version 2.11.1. (R Development Core Team 2010; www.R-project.org).

1.3 Results

1.3.1 Patients with donor evaluation, LDKT, or any transplant:

The 752 patients were followed for an average of 1.76 person-years. The fraction of all patients who had at least one donor evaluation was 28% at 100 days, 37% at 300 days,

41% at 600 days, and 51% at 1500 days (data not shown). These same fractions for the time from patient evaluation to LDKT were 3%, 10%, 15%, and 17%, and for the time from patient evaluation to any transplant were 4%, 12%, 21%, and 31% (data not shown). During the study, 102 LDKT and 62 deceased-donor transplants were performed in the study cohort.

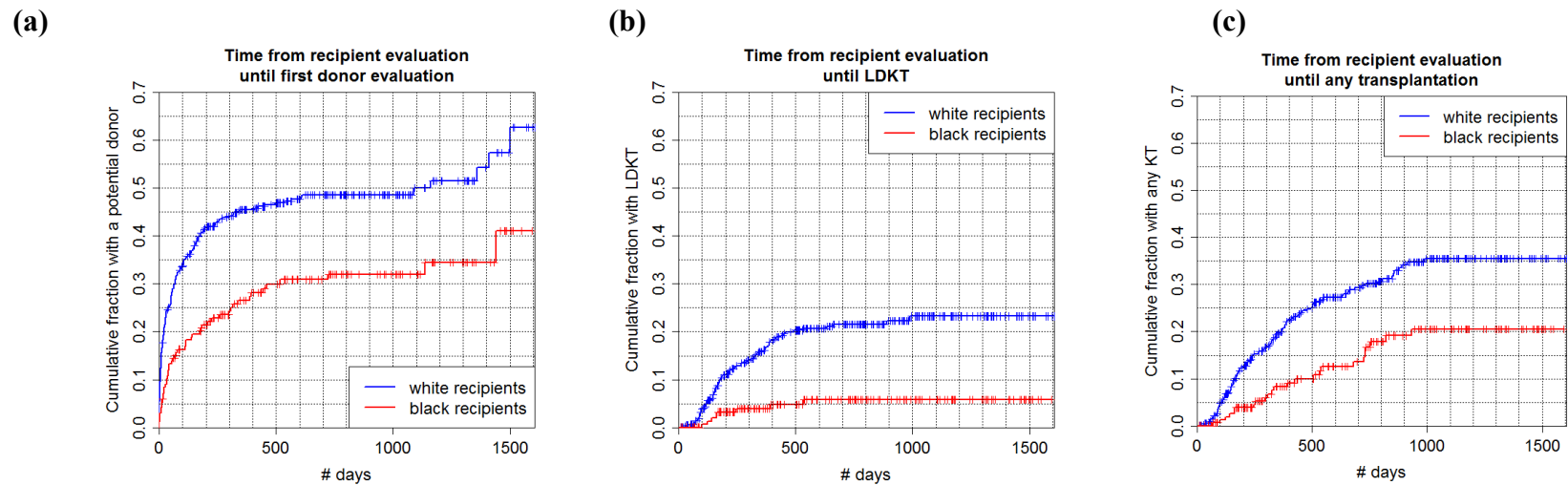
Table 1.1 displays a large gap between white and black patients for each endpoint at 18 months after initial recipient evaluation.

Table 1.1: Cumulative percentage of potential recipients (95% CI) reaching each of the three endpoints within 18 months of initial transplant evaluation, by race.

	White patients (n=438)	Black patients (n=167)	P-value
A living donor evaluation	47 (42-52)	31 (23-38)	p<0.001
Living-donor transplantation	21 (16-25)	6 (2-9)	p<0.001
Any transplantation	27 (22-32)	13 (7-18)	p<0.001

Forty-seven percent of whites versus 31% of blacks had a potential donor evaluated within 18 months ($p<0.001$), resulting in LDKTs for 21% of white patients versus only 6% of black patients within 18 months ($p<0.001$). **Figure 1.1** displays the Kaplan-Meier curves illustrating the cumulative fractions of patients achieving the three specified endpoints stratified by race. The log-rank test for differences shows blacks receiving fewer donors, LDKTs, and any transplant at all time points ($p<0.001$). **Figure 1** not only demonstrates a significant racial disparity, it also highlights a critical time period for donor presentation. After six months, the likelihood of donor presentation drops significantly for both whites and blacks, although more rapidly for whites.

Figure 1.1: Race-stratified Kaplan-Meier estimators of (a) time from initiation of potential recipient evaluation to initiation of evaluation of first potential donor, (b) time from initiation of potential recipient evaluation to LDKT, (c) time from initiation of potential recipient evaluation to any transplant (living or deceased)



The log-rank test for a difference in waiting times between white and black recipients was statistically significant ($p < 0.001$) for every endpoint.

Table 1.2 illustrates bivariate associations of patient characteristics and donor presentation by race. In white patients, marriage ($p<0.01$), younger age ($p<0.05$), and having more children and siblings were positively correlated with donor presentation.

Table 1.2: Bivariate associations of recipient characteristics and donor presentation, by race

		White patients			Black Patients		
		N (%)	Hazard ratio (95% CI)	p-value	N (%)	Hazard ratio (95% CI)	p-value
Male		267 (61)	0.80 (0.61-1.06)	0.12	87 (52)	0.84 (0.48-1.47)	0.55
Married		265 (60)	1.77 (1.29-2.43)	0.008	66 (40)	0.61 (0.32-1.14)	0.19
ADL Limitations		33 (8)	0.74 (0.40-1.46)	0.35	13 (8)	0.27 (0.04-1.99)	0.22
FT Employed		167 (38)	1.66 (1.24-2.22)	0.0007	46 (27)	1.39 (0.77-2.49)	0.26
ABO Blood type	A	166 (37)	0.91 (0.67-1.25)	0.71	46 (28)	0.84 (0.43-1.67)	0.57
	B	50 (11)	0.73 (0.41-1.30)	0.21	32 (19)	0.76 (0.34-1.67)	0.47
	AB	23 (5)	0.67 (0.29-1.53)	0.22	7 (4)	insufficient observations	
	O	199 (45)	Reference		82 (49)	Reference	
Non-smoker			Reference			Reference	
Currently Smoking		73 (17)	0.80 (0.49-1.33)	0.61	39 (23)	1.01 (0.43-2.37)	0.91
Non-drinker			Reference			Reference	
Currently Drinking		137 (31)	1.21 (0.88-1.66)	0.11	32 (19)	1.23 (0.47-3.22)	0.88
Psychiatric History		118 (27)	0.69 (0.48-0.99)	0.04	44 (27)	0.55 (0.27-1.15)	0.11
Hypertensive		344 (79)	0.57 (0.42-0.77)	0.0002	147 (88)	0.49 (0.25-0.99)	0.05
Peritoneal-dialysis			Reference			Reference	
Hemodialysis		270 (62)	0.55 (0.41-0.72)	<0.0001	127 (76)	0.71 (0.38-1.34)	0.29
Age	<50	158 (36)	Reference		75 (45)	Reference	
	50-59	112 (26)	1.28 (0.92-1.78)	0.14	52 (31)	0.40 (0.20-0.82)	0.01
	60-69	116 (26)	0.64 (0.44-0.93)	0.02	30 (18)	0.51 (0.22-1.15)	0.11
	70+	52 (12)	0.42 (0.24-0.75)	0.003	10 (6)	0.18 (0.02-1.31)	0.09
BMI	<25	155 (35)	Reference		52 (167)	Reference	
	25-29.9	119 (27)	0.93 (0.61-1.41)	0.86	49 (29)	0.74 (0.33-1.69)	0.31
	30-34.9	87 (20)	0.95 (0.56-1.59)	0.81	29 (18)	0.51 (0.18-1.44)	0.24
	>=35	77 (18)	1.08 (0.67-1.75)	0.70	37 (22)	0.92 (0.43-1.99)	0.84
Education	Less than college	169 (39)	Reference		97 (58)	Reference	
	College and above	269 (61)	1.15 (0.86-1.55)	0.26	70 (42)	1.43 (0.80-2.55)	0.18

(Table 1.2
continued)

Number of siblings	0-1	130 (30)	Reference		26 (16)	Reference	
	2-3	193 (44)	1.09 (0.75-1.60)	0.96	46 (27)	0.92 (0.28-3.01)	0.73
	>3	115 (26)	1.13 (0.76-1.70)	0.75	95 (57)	0.73 (0.26-2.07)	0.26
Number of children	0	106 (24)	Reference		28 (17)	Reference	
	1-2	195 (44)	1.11 (0.73-1.70)	0.53	53 (32)	0.56 (0.21-1.45)	0.22
	3-4	121 (28)	1.03 (0.70-1.53)	0.93	64 (38)	0.65 (0.29-1.47)	0.24
	>4	16 (4)	1.34 (0.44-4.12)	0.39	22 (13)	0.73 (0.25-2.09)	0.34

Note: Each hazard ratio based on a separate Cox model having only the variable as predictor. Hazard ratio greater than 1 indicates that the variable is associated with shorter wait to find a donor.

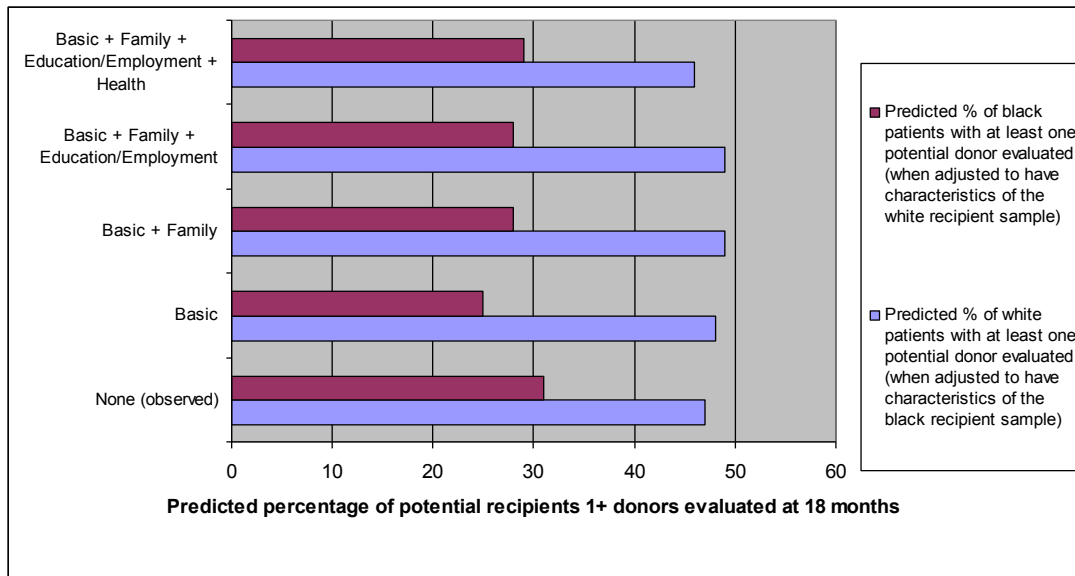
In blacks hypertension and age 50-59 and over 70 years were negatively correlated with this outcome, illustrating potentially distinct effects of covariates by race. To avoid bias stemming from the assumption that covariates affect whites and blacks identically, we examined what would happen to donor presentation rates if white patients exhibited the covariate distribution of black patients, and alternatively, if black patients exhibited the characteristics observed in white patients.

1.3.2 Adjustment of covariates to calculate counterfactual donor presentation rates if black patients had the characteristics of white patients

We performed the adjustment in stages, where the bottom columns are the references illustrating the observed percentage of black and white patients with at least one potential donor evaluated within 18 months. **Figure 1.2** shows that little, if any, of the gap observed between blacks and whites can be attributed to the usual predictor variables. For a hypothetical population of white patients with the distribution of predictor variables of blacks patients (Basic+family+education/employment+health), 46% would have had at least

one potential donor evaluated (nearly the same as the estimate observed in the actual white patients).

Figure 1.2: Cumulative percentage of potential recipients predicted to have at least one potential donor evaluated within 18 months of initiation of initial potential recipient transplant evaluation.



Notes: N= 605 patients (438 Whites, 167 Blacks)

Basic: Gender, Age

Family: Marital Status, Number of Siblings, Number of Children

Health: BMI, Drinking, Psychiatric History, Functional Limitations, Hemodialysis, Peritoneal Dialysis, Hypertension

For a hypothetical population of black recipients having the same predictor variables as the whites in our sample, 29% would have had at least one potential donor evaluated (approximately the estimate observed for the actual black patients).

1.3.3 Relationship and number of potential donors evaluated

The 654 potential donors evaluated yielded an average of 0.49 potential donor evaluations per recipient-year-on-study. Excluding seven donors whose gender was not

recorded, 43% were men and 57% were women. **Figure 1.3** displays the distribution of relationships of potential donors to patients, for those with data available.

Figure 3: Relationship and number of potential donors evaluated per 100 recipient-years on study, by race

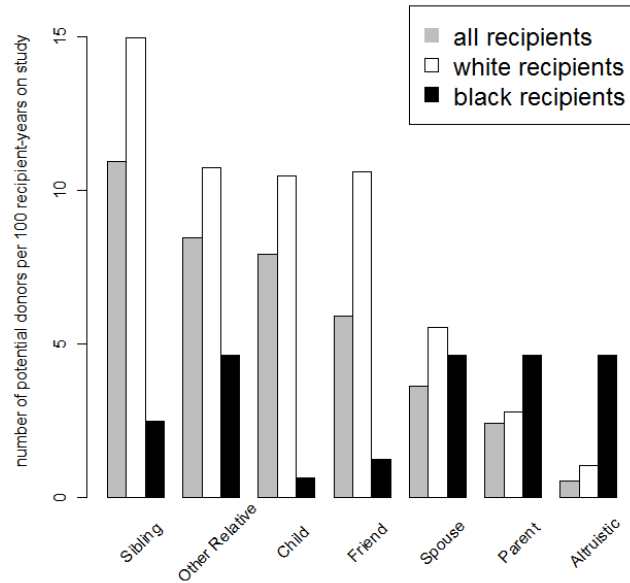


Figure 1.3 illustrates that, for 100 potential white patients waiting one year, on average, 15 siblings came forward to be evaluated, whereas only two siblings were evaluated for 100 potential black patients one year after being evaluated ($p < 0.001$). Black patients were more likely than white patients to have parents evaluated, and were nearly as likely to have their spouses evaluated. The distributions of potential donors evaluated were significantly different by race ($p < 0.001$). Though male patients had potential donors evaluated at just 70% the rate of female patients, they were more likely ultimately to receive a transplant ($p < 0.001$).

1.4 Discussion

Understanding the extent to which disparities in LDKT persist despite universal coverage is critical not only to improving quality in ESRD treatment, but also in the context of coverage expansions under the PPACA. Though coverage expansions proposed in PPACA present a first step to reducing racial disparities in healthcare, it seems unlikely that they will close the gap, based on evidence of lasting disparities in ESRD. Despite the overrepresentation of black patients among those with ESRD and awaiting renal transplantation, and despite the better graft survival rates associated with LDKT, white patients have benefited disproportionately from LDKT over the past decade. This is particularly concerning because black patients are likely to receive deceased-donor organs that are less well-matched, although this has improved with allocation policy changes, and thus could benefit from LDKT⁸. What mechanisms underlie the disparity in LDKT between blacks and whites? For at least twenty years, the disparities literature in transplantation has identified a comprehensive set of demand-side (recipient) factors thought to underlie disparities in transplantation, including: race, gender, and age^{19, 33}, enabling factors^{34, 35}, and health characteristics.³⁶ These studies suggest that if baseline factors were hypothetically redistributed between blacks and whites, such that blacks would have the same distribution of socioeconomic status (SES), health, and other important characteristics as whites, disparities in LDKT rates would disappear. Until now, however, there has been no actual modeling or data to answer this question.

We have demonstrated marked racial disparities in the cumulative percentage of patients who had at least one donor evaluated, underwent a LDKT, or had any transplant (**Table 1.1**). Disparities in the time to each of these endpoints persisted as well (**Figure 1.1**). Importantly, we found that the likelihood of donor presentation dropped precipitously six months after the initial recipient evaluation (**Figure 1.1**), suggesting that there is an initial

time-sensitive interval, during which interventions aimed at increasing donor presentation could be targeted. While for whites, the likelihood of a donor presentation declined significantly immediately after six months, for blacks the drop-off is less steep. All patients at BIDMC are told about LDKT when they begin their evaluation. Still, black recipients may wait longer before initiating conversations about LDKT with potential donors and, therefore black donors may learn later about LDKT or may need longer to come to a decision about undergoing donor evaluation. This warrants further study. Although clinical interventions aimed at increasing donation within this six-month period might be beneficial, it is also important to better understand why donor candidates are less likely to present for evaluation after the six-month period and how interventions might sustain interest and success in identifying willing and suitable donors. Overall a better understanding of how successful timing of interventions may differ by race is important.

Marital status, employment, and educational attainment correlate positively with donor evaluations, whereas psychiatric illness, hypertension, peritoneal dialysis, and older age correlate negatively (**Table 1.2**). However, the effect of these covariates varies by race. By using subclassification and race-specific regression models, we were able to expand upon prior findings suggesting that marital status, employment and higher socioeconomic status are beneficial in procuring a donor for all recipients, by demonstrating how these benefits vary by race^{11, 37, 38}. The data clearly demonstrate that disparities in rates of donor presentation track with race and cannot be explained by differences in commonly cited risk factors (**Figure 1.2**). Even if black patients have the baseline characteristics of white patients, the disparities would persist. This is the first time this has been shown. Unexpectedly, racial disparities in LDKT remain significant at every endpoint, suggesting that black patients do not “catch-up” even if they learn about LDKT upon initial evaluation.

This is particularly noteworthy because it illustrates that racial disparities persist even despite universal coverage and similar patient characteristics, suggesting that on supply-side (donor) differences may be important. There is data bearing on this hypothesis from Rodrigue et al. who have demonstrated an improvement in the rate of living-donor presentation among black patients after conducting home information sessions on living kidney donation for family and friends of the patient ³⁹.

We have also hypothesized that social networks may partially explain racial disparities in LDKT.⁷ Social networks have been shown to influence health outcomes through shared social capital, similar, group risky behaviors, shared social norms, and transmission of pathogens and disease.⁷ “Supply-side” characteristics, such as medical co-morbidities among potential donors have also been cited as a significant barrier to donation, particularly among underrepresented minorities.^{7, 20, 37} Differences in household composition in number of siblings and those who share both biological parents might explain why there are fewer related donors among the donors evaluated for black patients and why it takes longer to identify a live donor.^{40, 41} For blacks compared to whites, fewer related donors and friends came forward as donors, perhaps related to shared comorbidities, younger age at ESRD, or cultural differences (e.g. distrust in the health care system) (**Figure 1.3**). Socioeconomic disparities, which have been shown to affect health, healthcare, job security, and ability to take extended leave, are likely to have a large impact on ability and willingness to donate.^{42, 43} These factors remain significant (although their importance has diminished), despite the use of laparoscopic nephrectomy which reduces hospitalization and scarring, two factors previously cited as barriers to LDKT.^{42, 44}

Our findings should be interpreted in the context of the study limitations. First, the clinical encounter, size and health of recipients’ social network, perceived benefit, and

difficulty completing the evaluation process, might have influenced the disparities.^{45, 46}

Second, measurement of SES using education and employment status, not recipient income, is potentially limiting. Third, health care professionals may not be as aggressive in promoting transplantation among black patients, though it is unclear whether prejudice or statistical discrimination is at play.¹⁵ Though we have attempted to avoid provider-level bias by using single-center data, we cannot rule this out entirely. Given BIDMC's efforts in clinical outreach and research and clinical emphasis of mitigating disparities, prejudice (as opposed to statistical discrimination) seems an unlikely explanation. Despite the limitations of a single-centered study, namely that the results may not be generalizable to other centers and regions, our study has the distinctive strength by including linked donor characteristics that have typically not been available in prior national datasets. Finally, peer influences and timing of information may play a role, though we were unable to observe them in this study.

In conclusion, we have shown for the first time that racial disparities in transplantation would likely persist even if black patients had the characteristics of white patients and were universally insured. Our findings also suggest that early interventions and outreach during the first six months following patient evaluation may improve donor presentation, although sustained interventions to identify donors beyond this time might also be beneficial. Better understanding the pool of potential donors, along with their risks and decision-making process, is the next step necessary in reducing disparities.

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Chapter 2

How whom you know could save your life: Social networks and disparities in living donor kidney transplants

2.1 Introduction

Although racial disparities in renal transplantation have been widely documented for over thirty years, underlying causes of these disparities remain illusive. The majority of research examining disparities in renal transplantation has focused on individual-level factors. Although undoubtedly important, individual-level factors collectively explain only a small fraction of the variation in outcomes (5, 6) . An alternative explanation has been proposed, relying on evidence that social networks affect health outcomes and utilization (7, 8). A social network hypothesis suggests that the unexplained variation in living donor kidney transplantation (LDKT) rates may, in part, be due to fundamental differences in social networks of black and white patients. Social networks refer to the structure of social relationships, also called ties, and the connections between an individual and others with whom the individual interacts. Given that the likelihood of obtaining a LDKT is dependent on having a willing and able donor within the patient's network, systematic differences in the capacity or willingness of network members to donate could, in part, explain racial disparities in LDKT. This is the first study to examine social networks of black and white dialysis

patients, and the only study to include both patients and their social network members. The goal of this study is to investigate whether social network characteristics are associated with disparities in pursuing and obtaining a LDKT.

2.1.1 Scope of LDKT and racial disparities

Racial disparities in transplantation are pervasive and persistent, despite universal Medicare coverage. End stage renal disease (ESRD) disproportionately affects blacks, who suffer an incidence rate over three times that of Whites (9). Treatment for ESRD has become a growing public health concern. Between 1980 and 2009, the prevalence of ESRD increased nearly 600 percent. Medicare spending on ESRD rose 8% in 2010, exceeding Medicare's growth rate of 6.5%. Medicare expenditures for ESRD now exceed \$32.9 billion, approximately 6.3% of the Medicare budget (10). Currently, more than 80,000 Americans are awaiting kidney transplant (11). While LDKT is accepted as the best option for most persons facing kidney failure because of improved survival and quality of life at a significant cost benefit to the healthcare system, the 'gift of life' has not been evenly distributed. Blacks continuously face adversity in pursuing transplantation, as neither the risk or severity of renal disease, nor the quality or access to life-saving treatment are evenly distributed (12, 13). Blacks comprise over a third of the population needing a transplant, but receive just 11 percent of LDKTs in 2011 (11).

Thus far, efforts to address disparities in transplantation have focused on individual-level factors. Despite universal Medicare coverage, there is ample evidence that black patients suffer delays and lower quality treatment, incomplete workups, and lack of continuous access to care (1-4, 14). African-American race, lower income, and lower educational attainment were associated with lower odds of LDKT, and these differences

persist even among patient populations with access to a transplant center and who are able to navigate the complex transplant evaluation process and gain approval for surgery, (5). Reese et al. (2009) found that younger candidates and those with higher incomes were more likely to have a potential donor evaluated, and whites were more than twice as likely as blacks to have had a potential donor evaluated (15). One partial explanation stems from the disproportionate need among Blacks for financial assistance to overcome costs associated with LDKT (16). Provider and center-level factors have also been implicated. Numerous studies have documented physician bias and insufficient availability of culturally-sensitive education about transplantation as contributors to disparities (17). A recent study concluded that none of the transplant centers in the U.S. exhibited racial parity in rates of LDKT. Blacks experienced 35% lower odds of LDKT at centers with the least disparity compared to 76% lower odds at centers with the greatest disparity. Centers with higher percentages of Black candidates had higher racial disparity (18).

Although individual risk factors and provider/center characteristics contribute demonstrably to disparities in LDKT, these characteristics account for less than a quarter of the overall variation in LDKT rates (5). In fact, a recent study estimates that even accounting for medical, sociodemographic, and some familial characteristics does not account for the gap in LDKT between whites and blacks (6). Efforts to increase equity in access to LDKT have been met with only mild success. This may be partly because focusing on individual-level factors alone does not adequately correct for disparities, and results in a residual disparity (6). This residual disparity may be in large part do to differences in characteristics of their social networks.

2.1.2 Potential role for social networks and definition of network

Social networks have been shown to influence health outcomes through various pathways, including shared social capital; similar, group risky behaviors; shared social norms and transmission of pathogens or disease (19). Social networks can be characterized in different ways, including the availability of ties (number, proximity, and accessibility of ties), the structural characteristics of those ties (density, directionality, and other factors), the composition of ties (with kin versus nonkin, friendships, and ties gained through formal organizational linkages), and the efficacy of ties (the ability of ties to facilitate the transfer of resources). Social networks are especially likely to mediate LDKT rates because in this case the patient's ability to pursue treatment is directly related to the willingness and ability of his or her social network to donate.

Social networks can affect all stages of the LDKT process. The size and structure of social networks can directly affect a patient's ability to obtain a living donor kidney. A larger network, one with more ties, may afford the patient more opportunities to find a willing and able donor, whereas a small network, or at the extreme a person lacking any network, may never find a donor. Other network characteristics, like density, strength of ties, and health of network members, among others, may also be predictive of LKDT. Network composition may also be important because having a more diverse or open network may allow a patient to draw upon a diverse set of resources, and may be beneficial for information diffusion (20).

Little is known about social networks of dialysis patients or how social networks influence patient decision-making (21). Given that individuals are nested within social networks, their behavior, norms, resources, and health are all affected by their network (22). Belonging to a network with many high-risk individuals might impart disadvantage beyond the individual level by decreasing the patient's number of eligible donors. This could result

from either fewer people willing to donate (due to shared social norms, risk perception, or income insecurity following donation); or fewer eligible donors owing to poor health status (23, 24). This notion is supported by evidence that certain health characteristics, like obesity, smoking, and other precursors to kidney disease, can spread through networks (25, 26).

2.1.3 Hypothesis

We postulate that network characteristics explain, in part, being told about LDKT and successful pursuit of LDKT. We hypothesize that four aspects of social networks might influence LDKT: (1) compositional differences in the networks (i.e. size, strength of ties, reciprocity, and density) may limit the pool of available donors; (2) differences in information diffusion or knowledge about transplantation on the patient or social network-level may explain differences in pursuit of LDKT; (3) differences in medical mistrust may limit patients' willingness to ask for donation and network members' willingness to undergo donation; and (4) contra-indications of many members of social networks due to poor health and shared health behaviors may preclude them from donation.

2.2 Methods

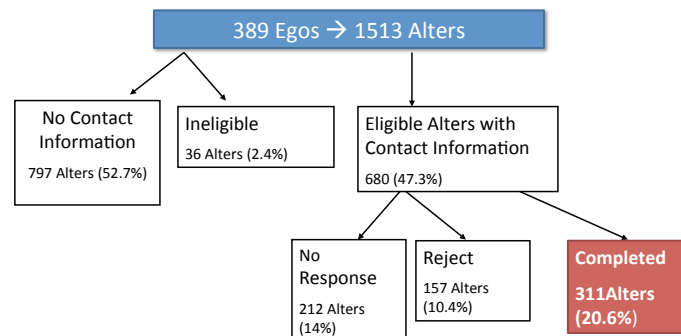
2.2.1 Sample

Patients (Egos): The sample includes 389 randomly sampled patients receiving out-patient hemodialysis treatment at thirteen centers in the Greater Boston area. Centers were selected based on patient volume and demographic characteristics, in an attempt to balance

patients by race and age.¹ Nurse coordinators pre-screened patients for eligibility and research staff verified eligibility using medical records. Eligibility criteria included: current dialysis treatment, age of 18 years or older, English fluency, mental and physical capacity to consent and participate. Participation rates ranged from 65.38%-86.67% by center, with average participation of 75.15% across the entire sample. A team of trained research assistants conducted the surveys while the patients received hemodialysis treatment. Alter interviews were conducted by phone. Institutional review board (IRB) approval of the study was provided by Harvard University, and approval for center participation was provided by the dialysis companies' corporate IRBs, their clinical research directors, and each center's medical director,

Alters: Patients listed 1,489 alters and 44 additional emergency contacts. Phone interviews were conducted with a random subsample of alters (20.6%) who had valid contact information (Figure 2.1).

Figure 2.1: Diagram of alter sampling strategy and subsample of alter participants



¹ This was achieved by receiving patient lists and demographic information from the nurse coordinator at each dialysis center. We oversampled Blacks and urban populations.

Alters were not provided the name of the patient who listed them as an alter. In total, 305 ego-alter pairs, and 201 egos are linked to at least one alter.²

2.2.2 Measures and analytic strategy

A survey instrument was developed for the purpose of this study since no data exists about social networks of dialysis patients. The structured survey interview lasted on average 38 minutes (range 20-120 minutes).³ The alter survey was similar but shorter, lasting only 10-15 minutes.

2.2.1 Independent variables

We examined patient's knowledge and attitudes about pursuing transplantation and LDKT, including whether they have sufficient information to make an informed decision about transplantation. For the purposes of this study, four binary outcome measures were used: (1) whether the patient had ever been told about LDKT, (2) whether the patient had explicitly asked an alter for donation, (3) whether the patient was actively pursuing transplantation (assessed using the following statement "I have thought about kidney transplantation, and I have talked to someone who is willing to be evaluated as a possible live donor"), and (4) whether the patient was actively pursuing transplantation with an identified donor (assessed using the following statement, "I have thought about kidney transplantation and I have someone who has already been evaluated and approved to be a live donor"). Statements

² 23 additional pairs can be obtained using emergency contact information.

³ This large range is primarily due to the number of alters named (social network questions are a loop).

about LDKT readiness were compiled from a validated survey of transplant readiness that has been widely used with vulnerable populations (27).

2.2.2 Dependent variables

Social Network Attributes

Network size: The patient's social network was generated using standardized and widely used social network name generators which ask respondents to reflect and name people with whom they discuss important matters and with whom they spend their free time (28). Using these questions, patients identified up to six adults (social network members, hereafter referred to as alters) and answered questions about their alters and their relationships. A list was compiled by including a maximum of 6 alters, and in case more than 6 alters were named, the patient selected from the list.

Local Density: Local density reflects the fraction of alter pairs who are connected in a given ego's network, and is a measure of connectedness often associated with information diffusion and certain types of support. Local density, a measure of network openness, was estimated by dividing the number of alter-alter connections by the total number of possible connections in the network.

Closeness: Closeness was assessed using the validated question, "On a scale of 1 to 10 (one representing not close at all, and 10 representing closer than anyone else) how close do you feel to ____?" Similarly, the patients are asked, "On a scale of 1 to 10, how much does ____ make you feel liked or loved (1 representing the alter not making you feel liked/loved and 10 representing that the alter makes you feel liked or loved more than anyone else)".

Additional variables:

Medical Distrust: Medical distrust was measured using the Revised Health Care System Distrust Scale (29) (Cronbach α 0.83 overall, 0.87 among whites, 0.82 among Blacks) (29). The scale includes 2 validated subscales: values distrust (5 items; Cronbach α : 0.73 overall, 0.77 among whites, 0.73 among Blacks) and competence distrust (4 items; Cronbach α 0.77 overall, 0.79 among whites, 0.77 among Blacks). Values distrust encompasses beliefs about the honesty, motives, and equity of the health care system and includes items such as “The health care system puts making money above patients’ needs” and “The health care system covers up its mistakes.” Competence distrust encompasses beliefs about the technical ability and performance of the health care system and includes items such as “The health care system does its best to make patients better,” and the “The health care system makes too many mistakes.”

Information about network structure, social support, health behaviors, and sociodemographic information was collected for each patient and alter. Assets were estimated using the following validated question from the Health and Retirement Survey, “Finally, please take a moment to estimate your household's total investable assets. These are "liquid" assets, including savings, CDs, mutual funds, stocks, and bonds. Investable assets exclude real estate, business holdings, and employer-sponsored retirement plans, such as 401k plans.” Liquid assets were included because they are often a requirement for transplantation, and a good measure of socioeconomic status. Patients also noted whether or not they knew someone who had experience with transplantation. Health characteristics (including self-reported health, BMI, diabetes, hypertension, cardiovascular disease, psychiatric history, adherence, creatinine levels, infections, time on dialysis, and pain) were self-reported by patients, and were verified using medical records. Alters self-reported health

characteristics, including diabetes, BMI, self-rated health, hypertension, chronic kidney disease, quality of life, and expectations for future health.

2.2.3 Analysis

Data was analyzed using Stata version 11.2. Univariate, bivariate, and multivariate analyses were used to examine racial disparities at both the ego- and alter levels. Given how little is known about the structure and characteristics of dialysis patients' networks, descriptive statistics characterizing the networks and illuminating relevant differences (or overlaps) is novel and furthers current understanding of the decision-making process. Correlations between dependent and outcome variables were analyzed using t-tests for continuous variable and Fisher's exact test or chi-square test for categorical variables. Logistic regression analyses were conducted to estimate the relationship between social network characteristics and LDKT outcomes. Models controlled for age and gender.

2.3 Results

Characteristics of the study participants are shown in Table 2.1.

Table 2.1: Sample Characteristics

		Overall (n=355)	Black (n=161)	White (n=194)	p
Male (%)		59.69	49.36	67.2	0.008
Age (%)					
	18-30	2.88	4.14	1.6	
	31-40	2.31	3.55	1.07	0.098
	41-50	10.7	16.77	5.67	0.0007
	51-60	20.11	25.63	15.54	0.0186
	61-70	22.25	21.11	23.2	
	71-80	20.06	20.1	20.45	
	>80	21.69	8.7	32.47	0.0001
Education (%)			100		
	High school or less	50.53	63.58	42.47	0.0075
	Some college	22.46	21.85	27.96	
	College or higher	27.01	14.57	29.57	0.008

(Table 2.1 Continued)

Assets (%)					
	<10,000	53.16	69.84	40.94	0.007
	\$10,000-\$50,000	21.93	19.05	23.49	0.05
	\$50,000-\$100,000	9.63	7.14	12.75	0.01
	\$100,000-\$250,000	7.64	2.38	10.07	0.0001
	\$250,000-\$500,000	3.99		6.71	
	\$500,000-\$1 million	1.99	1.59	2.68	
	\$1 million-\$2 million	1.33		2.68	
	\$2 million +	0.33		0.67	
Health Insurance (%)					
	Private	36.42	27.01	45.73	0.0001
	Medicare	41.98	42.34	42.07	0.0001
	Medicaid	21.6	30.66	12.2	0.0001

Black and whites patients had similar distributions of age, sex, and health care measures, however, Blacks were significantly younger, less likely to have a college degree or higher, less likely to be married, and were more likely to have few assets. Alters were significantly more likely to be younger, employed, and better educated than their respective egos.

2.3.1 Descriptive statistics depicting social network differences, by race

Structural and Compositional Differences

Structural and compositional characteristics of ego-reported networks did not differ significantly by race (Figure 2.2). Both groups named a mean of 3.8 alters (Table 2.2), though Blacks were more likely to name the maximum of six alters than Whites (29.81% versus 22.87% respectively, $p=0.14$).

Figure 2.2: Ego and Alter Network size, by race

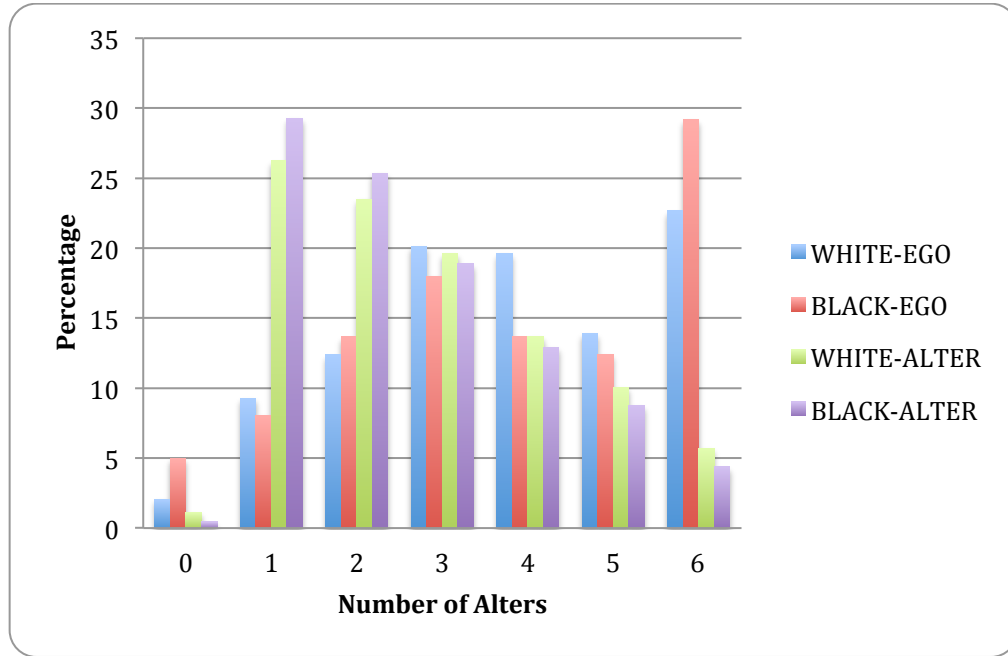


Table 2.2: Ego-level network structural differences, by race

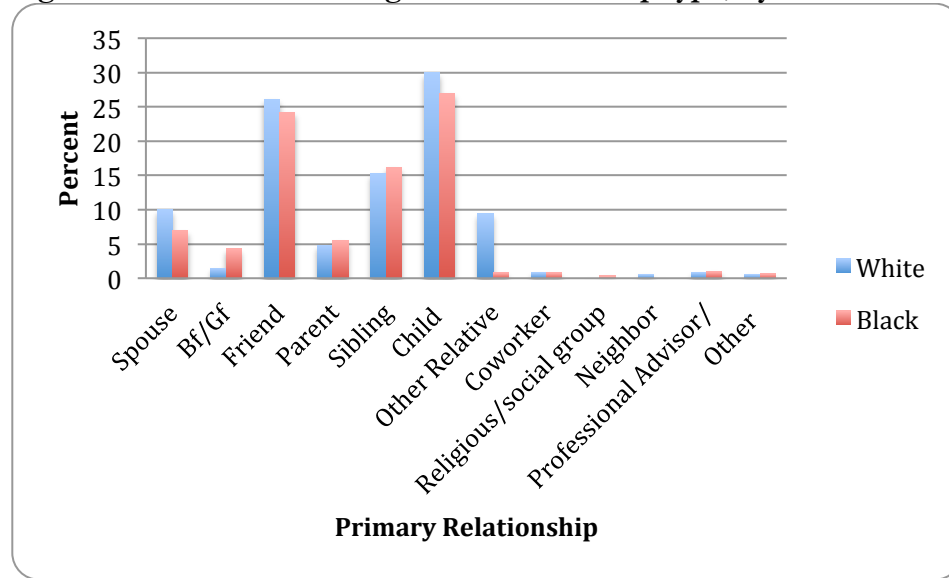
	White	Black	Total	Difference	p-value
Network size	3.87	3.886	3.879	0.016	0.947
(Std Err)	(1.767)	(1.905)	(1.840)		
Network density	0.851	0.881	0.864	0.03	0.309
	(0.269)	(0.248)	(0.260)		
Reciprocity	0.458	0.504	0.482	0.045	0.473
	(0.500)	(0.502)	(0.501)		
Length of time living in city	28.38	18.729	23.143	9.651	0.0009
	(22.549)	(20.393)	(21.894)		
Average Like (1-10)	9.405	9.487	9.442	0.082	0.464
	(0.881)	(1.148)	(1.009)		
Average Close (1-10)	8.982	9.15	9.056	0.168	0.238
	(1.252)	(1.308)	(1.279)		
<i>n</i>	108	132	240		

Blacks reported feeling closer to their alters than Whites (9.20 vs 8.98 out of 10, $p=0.11$), and were more likely to live in the same city as their alters (27.94% versus 14.82%,

$p < 0.05$), indicating concordance in geographic and geodesic strength of ties. Nearly a quarter of black alters resided in the same household as the patient (16.78% of Whites, 22.68% of Blacks, $p < 0.05$). Networks of black patients were only slightly denser than White's (0.85 Whites, 0.88 Blacks, $p = 0.308$), however, 73.2% of Blacks had a network density equal to 1, compared to only 67.1% of Whites ($p < 0.05$). No racial differences in closeness between egos and alters were observed.

Although at the patient-level few explanatory differences emerged, alter networks varied more. Alter networks were significantly smaller than patient networks, consisting of 2.6 social network members on average (2.71 for white alters vs 2.58 for black alters, $p < 0.05$). Alter networks were less dense than patient networks, with white alter networks significantly more open than blacks'. Black alters were closer to each other than those in White networks (7.03 and 6.12, respectively, $p < 0.05$), strengthening the notion that White networks are more open with fewer ties between alters and, weaker ties when they exist. Black and white patients differed slightly in the type of relationships they had with their alters. Blacks were less likely to name a spouse, child, friend, or non-immediate family member, but were more likely to name a parent or sibling (Figure 2.3).

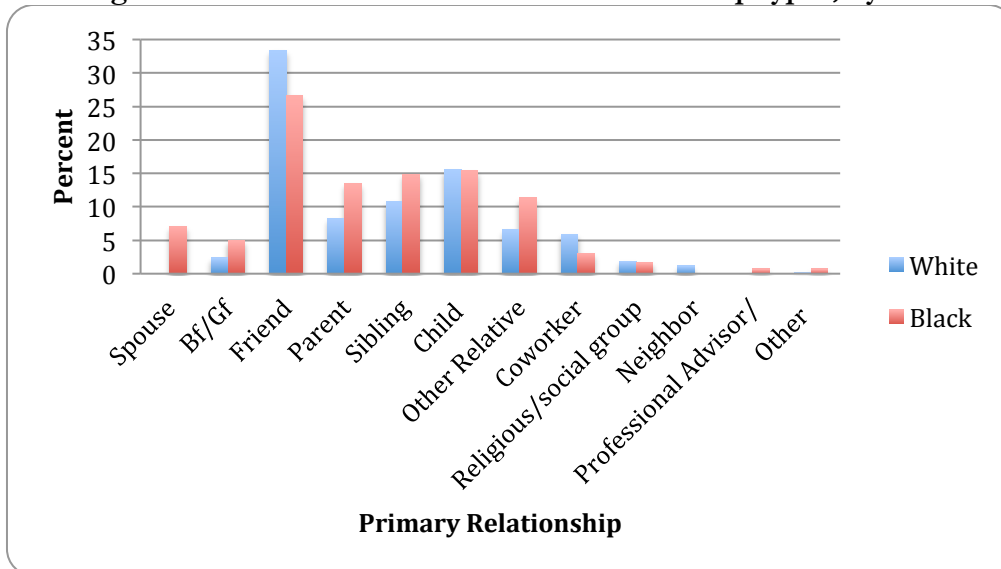
Figure 2.3: Distribution of ego-alter relationship type, by race



Significant at Chi-squared<0.01

Differences seen at the patient level were heightened at the network level (Figure 2.4), with whites naming significantly more friends and coworkers than blacks.

Figure 2.4: Distribution of Alter-Alter relationship types, by race



Significant at Chi-squared<0.01

In contrast to the patient level, blacks named more parents, siblings, and other relatives than whites (chi-squared<0.01).

Information about transplantation

Social networks are important in facilitating information diffusion, elucidating how people learn about new information. The overwhelming majority of patients were informed about transplantation and LDKT, with most reporting that these were good therapeutic options for patients with ESRD. When asked about how they first learned about transplantation and LDKT and with whom they first discussed this, Whites most commonly first learned about transplantation from their nephrologist (67.9% of whites versus 57.3% of blacks, $p<0.05$). Blacks were more likely than Whites to learn about transplantation from their transplant psychologist or social worker, and dialysis center staff, indicating that they learned about transplantation later than Whites, either during their dialysis process (psychologist and dialysis staff), or from their PCP. Information diffusion related to LDKT displays similar trends; 63.5% of Whites reported learning about LDKT from their nephrologists, compared to only 53.5% of Blacks ($p<0.05$). Blacks were more likely to discuss LDKT with their alters (52.3% versus 35%, $p<0.01$), and both groups discussed this option frequently with their alters. Alters were generally well educated about transplantation being the optimal therapy for ESRD. Despite being more frequently approached by patients, black alters were significantly less informed than white alters about LDKT as a therapeutic option for ESRD (85% versus 94%, $p=0.02$)

Medical mistrust

There were no significant racial differences in medical mistrust among dialysis patients. All patients reported high levels of trust related to both competence of healthcare providers and their values (Table 2.3).

Table 2.3: Mean ego-level and alter-level distrust in healthcare scores, by race

Ego-level mean distrust in healthcare score					
	White	Black	Total	Difference	p-value
Overall Distrust	23.836	24.525	24.129	0.689	0.336
(Std Err)	(5.468)	(5.292)	(5.393)		
Competence Distrust	9.719	9.61	9.672	0.109	0.77
	(3.031)	(2.486)	(2.807)		
Values Distrust	14.119	14.92	14.46	0.801	0.06
	(3.127)	(3.32)	(3.228)		
<i>n</i>	134	99	240		

Alter-level mean distrust in healthcare score					
	White	Black	Total	Difference	p-value
Overall Distrust	23.538	26.923	25.305	3.385	0.00001
(Std Err)	(5.46)	(6.624)	(6.315)		
Competence Distrust	9.483	10.855	10.199	1.372	0.0003
	(2.858)	(3.064)	(3.04)		
Values Distrust	14.059	16.091	15.124	2.032	0.00001
	(13.454)	(15.381)	(14.64)		
<i>n</i>	119	130	249		

Despite the lack of disparities in medical distrust among egos, significant racial disparities in medical mistrust pervaded the social networks. Overall trust, as well as both the competence and values distrust subscales were significantly higher among Blacks when compared to Whites ($p < 0.0001$), with a mean overall distrust score of 26.9 among Black alters compared to 23.5 among Whites (Table 2.3). Disparities were especially large for values distrust, which reflect how much participants trust the intentions and personal character of healthcare providers.

Health

Disparities in health status were pervasive, both at the individual and network levels, with 51.3% of Black patients reporting that their health was fair or poor, compared to only 42.6% of Whites ($p < 0.05$) (Table 2.4).

Table 2.4: Ego-level health characteristics, by race

	Whites	Blacks	Difference	Total Sample	p-value
Means					
Happiness (1-10)	2.565	2.773	0.21	2.659	0.05
(std dev)	(0.070)	(0.080)		(0.053)	
Pain (1-10)	3.818	4.431	0.614	4.092	0.06
	(2.841)	(3.028)		(2.938)	
BMI	26.871	28.638	1.766	27.676	0.036
	(7.511)	(7.564)		(7.575)	
Time on dialysis (days)	905.406	1407.477	502.071	1134.447	0.00001
	(841.496)	(1345.636)		(740.951)	
Creatinine Level	7.386	10.313	2.927	8.747	0.00001
	(2.522)	(3.334)		(3.269)	
Frequencies					
Psychiatric illness	0.233	0.322	0.089	0.274	0.07
	(0.424)	(0.469)		(0.447)	
Diabetes	0.464	0.62	0.156	0.535	0.0045
	(0.5)	(0.4)		(0.5)	
Hypertension	0.95	0.923	0.0274	0.937	0.303
	(0.219)	(0.268)		(0.243)	
Heart Disease	0.636	0.463	0.173	0.556	0.002
	(0.483)	(0.5)		(0.498)	
Infection Rate	0.088	0.24	0.152	0.158	0.0002
	(0.284)	(0.428)		(0.365)	
Substance abuse	0.093	0.2	0.107	0.142	0.006
	(0.291)	(0.401)		(0.35)	
Poor adherence	0.048	0.166	0.117	0.103	0.0007
	(0.215)	(0.373)		(0.305)	
Self-rated health (good or better)	0.211	0.118	0.093	0.169	0.02
	(0.409)	(0.324)		(0.375)	
<i>N</i>	<i>194</i>	<i>161</i>		<i>355</i>	

Note: All from medical record review except self-reported health

Blacks were significantly more likely to have higher BMIs, higher creatinine levels, and higher rates of diabetes, psychiatric illness, substance abuse, poor adherence, and infections ($p < 0.05$). After adjusting for age, these disparities persisted (Table 2.4). When rating the average amount of pain felt in the last month, with 1 being no pain, and 10 being very severe pain, Blacks, on average reported 4.43, while Whites reported 3.81 ($p = 0.057$).

Alters of black patients were in worse health than alters associated with white patients in ways that may preclude them from being living donors. Just 32.9% of Black alters reported being in very good or excellent health, compared to 50.6% of White alters ($p<0.01$). Black alters exhibited significantly higher BMIs, higher rates of diabetes, both contraindications to living donation. Black alters also reported lower overall quality of life than Whites (Table 2.5).

Table 2.5 Alter health characteristics, by race					
	White	Black	Total	Difference	p-value
Means					
Diabetes	0.1667	0.226	0.198	0.059	0.242
(std dev)	(0.374)	(0.42)	(0.399)		
BMI	28.505	30.691	29.657	2.19	0.008
	(5.834)	(6.801)	(6.442)		
Self-rated health (1, excellent-5 poor)	2.475	2.917	2.705	0.442	0.0006
	(1.003)	(1.008)	(1.028)		
Quality of Life (1-10)	7.837	6.938	7.367	0.900	0.0004
	(1.771)	(2.121)	(2.010)		
Frequencies					
Self-rated health good or better	0.833	0.699	0.768	0.134	0.01
	(0.374)	(0.460)	(0.426)		
Hypertension	0.317	0.417	0.369	0.100	0.101
	(0.467)	(0.495)	(0.484)		
Chronic Kidney Disease	0.0167	0.03	0.237	0.013	0.49
	(0.129)	(0.171)	(0.152)		
Expect health to worsen in the next year	0.444	0.233	0.333	0.389	0.0002
	(0.046)	(0.037)	(0.030)	0.212	0.0004
<i>N</i>	<i>120</i>	<i>133</i>	<i>253</i>		

Note: All from medical record review except self-reported health

Black egos perceived their alters to be in worse health (on a scale of 1 to 5), estimating that only 44.3% of Black alters in very good or excellent health, versus 55.8% of White alters ($p<0.05$). Interestingly, when asked about the health of their alters, Black alters

overestimated the health of their alters significantly, and there was generally no correlation between the ego's perception of their alters' health and the alter self-reported health.

2.3.2 Regression Models with LDKT outcomes

Logistic regression models estimated the effect of social network characteristics on four outcomes: being told about LDKT, explicitly asking an alter for donation, actively pursuing an evaluation LDKT, and actively pursuing LDKT with an identified donor. These outcomes were chosen because they represent various critical points along the clinical pathway to LDKT. All models adjusted for age and gender.

Social network size was consistently a positive and significant predictor across all LDKT outcomes (Table 2.6).

Table 2.6: Model 1: Relationship between social network characteristics and being told about LDKT

Told about LDKT	OR	Std Err	P-value	95% Confidence Interval	
Total Alters	1.308**	0.116	0.002	1.099	1.556
Density	1.951	0.98	0.183	0.729	5.22
Average Alter closeness	0.719**	0.093	0.011	0.559	0.926
Know someone with tx experience	2.464***	0.628	<.0001	1.495	4.061
<i>n</i>				317	

***p<0.001; **p<0.01, *p<0.05, +p<0.1; Adjusted for age and gender

Social network size, captured by the total number of alters, was positively associated with being told about LDKT (OR 1.31, p=0.002), while average closeness to alters was negatively associated with being told about LDKT (OR 0.719, p=0.011). Adjusting for age, gender, marital status, and race, average alter closeness remained a significantly inversely associated with being told about LDKT (Table 2.7).

Table 2.7: Model 2: Relationship between social network characteristics and being told about LDKT, adjusting for marital status and race

Told about LDKT	OR	Std Err	P-value	95% Confidence Interval	
Total Alters	1.120	0.151	0.403	0.859	1.459
Density	1.191	0.816	0.799	0.311	4.563
Average Alter closeness	0.694*	0.111	0.022	0.508	0.948
Know someone w tx experience	2.692***	0.839	0.001	1.461	4.960
Average Alter Education	1.058	0.136	0.660	0.822	1.736
Married	0.938	0.294	0.840	0.507	1.736
Black	0.710	0.662	0.714	0.114	4.412
Black*Total Alters	1.131	0.300	0.238	0.837	2.054
<i>n</i>	226				

***p<0.001; **p<0.01, *p<0.05, +p<0.1; Adjusted for age and gender

Having more alters was more beneficial to blacks compared to whites, although this was not significant. In a third specification adjusting for socioeconomic status (liquid assets), network size and knowing someone with transplant experience were strongly associated with being told about LDKT ($p<0.05$), whereas alter closeness was negatively associated with LDKT. In contrast to its positive effect for Blacks, having a large network was negatively associated with being told about LDKT for patients with few assets (as opposed to those with more than \$10,000 in liquid assets).

Network size and knowing someone who had experienced transplantation were strongly associated with requesting donation, even after adjusting for marital status and race (OR 1.67, $p<0.001$ and OR 2.72, $p<0.005$ respectively, Table 2.8), and socioeconomic status (OR 1.74, $p<0.01$ and OR 2.49 $p<0.01$, Table 2.9).

Table 2.8: Relationship between social network characteristics and asking for donation, adjusting for marital status and race

Asked for donation	OR	Std Err	P-value	95% Confidence Interval	
Total Alters	1.671***	0.259	0.001	1.233	2.265
Density	1.083	0.788	0.913	0.26	4.509
Average Alter closeness	0.848	0.142	0.323	0.611	1.176
Know someone w tx experience	2.727**	0.968	0.005	1.356	5.469
Average Alter Education	0.867	0.121	0.307	0.659	1.140
Married	0.836	0.290	0.605	0.423	1.650
Black	12.346*	12.707	0.015	1.642	92.814
Black*Total Alters	0.673 ⁺	0.163	0.102	0.418	1.081
<i>n</i>	180				

***p<0.001; **p<0.01, *p<0.05, ⁺p<0.1; Adjusted for age and gender

Table 2.9: Relationship between social network characteristics and asking for donation, adjusting for marital status and few assets

Asked for donation	OR	Std Err	P-value	95% Confidence Interval	
Total Alters	1.741**	0.323	0.003	1.210	2.504
Density	1.755	1.246	0.428	0.436	7.058
Average Alter closeness	0.854	0.136	0.32	0.625	1.166
Know someone w tx experience	2.493**	0.853	0.008	1.276	4.874
Average Alter Education	0.870 ⁺	0.120	0.311	0.664	1.139
Married	0.698	0.239	0.294	0.356	1.367
Assets < \$10,000	3.005 ⁺	3.081	0.283	0.403	22.419
Low Assets*Total Alters	0.663	0.157	0.084	0.416	1.056
<i>n</i>	187				

***p<0.001; **p<0.01, *p<0.05, ⁺p<0.1; Adjusted for age and gender

Greater closeness with alters was negatively associated with asking for donation, although not significantly. In contrast to learning about LDKT where having larger networks seemed to slightly benefit blacks, having a larger network size was more not particularly beneficial to blacks or patients with low assets in asking an alter to donate. Even after adjusting for age, gender, race, insurance status, marital status, education, and assets, social network variables were significant in predicting whether a patient asked a social network member to donate (results available by request).

Among patients actively pursuing an evaluation for LDKT and among those who had already successfully identified a donor, network size was also a strong and significant predictor.

2.4 Discussion

This study provides a first step in understanding the relationship between social networks and LDKT and racial disparities in LDKT. The findings suggest that social network characteristics are associated with all stages of the LDKT process, including information diffusion, asking someone to donate, pursuing an evaluation, and successfully identifying a potential donor. In many cases, these effects persist even after adjusting for individual level characteristics. Network effects are largely explained by the size of social networks (the number of alters) and whether the patient knows someone who has experienced transplantation. Similar to prior studies, we find that density was not predictive of LDKT outcomes, but rather that size and the interaction of network size with race and socioeconomic status that is most important (21).

Closeness of alters was negatively associated with LDKT outcomes. This has important implications for transplantation, as weaker ties are thought to be more effective in supporting instrumental actions, such as the procurement of something that the ego does not yet possess, often new job or connection, and in this case a kidney (20, 30). In the unique case of LDKT, although strength of ties and closeness might intuitively seem to facilitate success, weaker ties are associated with more beneficial outcomes. Patients with close relationships may be overly concerned about burdening their alter and with potential harm. For Black patients, who had large networks with alters with whom they are very close, network size, not strength of ties was most beneficial in learning about living donation. Clinical implications include encouraging patients “to cast a wide net” when attempting to find suitable donors. Social network name generators, such as the ones used in this study,

could be adapted for clinical use. For example, social workers could use these as a tool to help patients determine an outreach strategy. Furthermore, patients should be counseled to continue to participate in their daily activities and engage with their network to the extent possible. These findings suggest that network size buffers some of disadvantage vulnerable populations may face, as having a large social network is disproportionately beneficial for black patients in learning about LDKT. It does not buffer vulnerability associated with low socioeconomic status or for other LDKT-related outcomes. This could be due to the smaller number of patients reaching those outcomes. Future research should explore potential explanations for this finding.

This study is the first to document significant disparities in health status and medical mistrust levels among social networks of dialysis patients. High rates of contraindications to donation among black alters are especially concerning because they suggest that, even if willing to donate, black patients are less likely to find suitable donors among their network members. Mean BMI among black alters exceeds the BMI threshold for living donation (generally the cutoff is 28). Higher rates of diabetes and hypertension were also concerning, especially because black alters were younger than white alters. Given that these characteristics are considered to be precursors to kidney disease, these findings suggest that health characteristics of dialysis patients are strongly predictive of the health of their networks. Despite this, black alters were more optimistic about their future health than white alters, suggesting that they may not be aware of long-term consequences of these conditions. From a public health standpoint, one implication may be that campaigns to prevent kidney disease could target the social networks of individuals with ESRD. These individuals may be most likely to benefit, not only due to their disproportionate need, but also because being

closely associated with a dialysis patient may increase the salience of health consequences related to diabetes and obesity.

Patient perceptions of their alters' health may play an important role in predicting whether they will ask for donation. Black egos perceived their alters to be in worse health (on a scale of 1 to 5), estimating that only 44.3% of Black alters in very good or excellent health, versus 55.8% of White alters ($p < 0.05$). Interestingly, Black alters overestimated the health of their alters significantly. There was generally no correlation between the ego's perception of their alters' health and the alter self-reported health. This finding is clinically important because it too suggests that patients should search widely and that all alters should be contacted. In particular, this finding illustrates that patients are very poor at estimating the health of their alters, and may unnecessarily rule out eligible donors.

Medical mistrust plays an important role in the process of care. High levels of medical mistrust are associated with lower health care utilization and lower rates of surgery (29, 31, 32). In this study, findings related to medical mistrust were mixed. On the one hand they reveal comparable levels of trust among ESRD patients, but higher levels of mistrust among black alters. Disparities in medical mistrust among alters of black patients is significant for two reasons. First, this finding suggests that even if eligible, black social network members may be less willing to donate because of their underlying distrust of health care professionals. Second, the low levels of medical mistrust among black patients is equally important in suggesting that disparities in mistrust may be a malleable trait, likely with greater exposure and immersion in the health care system. Several dialysis patients reported members of their clinical team (mostly social workers) as part of their social network. Qualitative observations suggest that repeated exposure to a clinical environment, in this case, a dialysis clinic combined with a multi-disciplinary care team, may be associated

with higher levels of trust among Black patients. This should be explored in future studies. Unfortunately, unlike health attributes which are similar for egos and alters, trust does not appear to be affected through social networks. Future research should examine whether positive spillover effects of improvements in trust among patients can be affect their alters, and more specifically whether patients can be engaged in trust-building interventions with their alters.

Surprisingly, we did not find disparities in knowledge about LDKT or transplantation as a treatment option documented elsewhere in the literature (23, 33). In fact, black patients were more likely to report knowing about LDKT and were more likely to express interest in pursuing this option. While this finding is in contrast to LDKT to national data, this may be because the Greater Boston area is uniquely saturated with transplant centers and virtually all dialysis centers were affiliated with a major academic medical center providing transplantation services. In contrast to previous studies, having an alter that is educated about LDKT and other treatment options does not explain variation in LDKT outcomes (21). Educational attainment (at either the patient or network level) was not associated with LDKT outcomes. This may be due in part to the substantial time spent on dialysis, perhaps attenuating differences that were larger at the point of initiation of dialysis. Especially for Black patients, this seems significant. Compared to blacks, few whites reported learning about transplantation from PCPs, friends, or family, but rather from their medical staff, primarily nephrologists. This reinforces the notion that Blacks may learn about LDKT later in the disease process, and often from someone other than a member of their renal care team, potentially resulting in lower quality of information, incomplete information, or missing information. Perhaps most importantly, having a network member who has had experience with transplantation is an important predictor of pursuing LDKT.

Although the benefit of an organic connection with an alter who has experienced transplantation may be greater, clinical interventions aimed at increasing patient exposure to transplant recipients may also help.

Although this study suggests an important role for social networks in explaining the pursuit of LDKT, it has two notable limitations. First, the sample was restricted to the Greater Boston area, and findings may not be generalizable to other contexts. This may be particularly true due to the large number of transplant centers in the region, universal healthcare insurance enacted in 2006, and the racially diverse population in the city of Boston. Second, although numerous outcomes related to successful LDKT were examined, too few patients received a LDKT within the one year follow-up timeframe for the results to be analyzed. As such, these cross-sectional data represent a single time point and causal conclusions are beyond the scope of this paper. Future studies should examine how social networks are related to long-term outcomes, namely receipt of LDKT.

This novel use of social networks to understand disparities in LDKT has taken us much deeper towards understanding the pathways that mediate LDKT disparities. To promote LDKT effectively, patients' social networks must be taken into account and barriers, namely poor health and medical mistrust, must be directly addressed. In themselves, social networks characteristics are powerful predictors of a patient's ability to successfully receive LDKT. These network effects may vary by group, and better understanding the interactions will help shape successful interventions. Interventions aimed at strengthening the networks of vulnerable patients by facilitating increased participation in community activities and employment could help reduce disparities. Furthermore, interventions aimed at augmenting the networks of vulnerable patients by introducing them to people who have experienced transplantation may also be beneficial. Finally, given the high prevalence of

health risks among social networks of dialysis patients, social network methods could be harnessed as an identification strategy for high-risk patients. This study ushers in a substantial research agenda to try and more systematically identify the decisive elements of social networks using longitudinal and qualitative methods.

Chapter 3

**The moral relevance of social networks: The case
of racial disparities in living donor kidney
transplantation**

3.1 Overview

Despite disproportionate need and greater benefit, African-American patients who comprise over a third of the waiting list receive only 13% of living donor kidney transplants (LDKTs). As the scarcity and wait times for deceased-donor organs increase, patients are increasingly turning to living-donor kidney transplantation (LDKT) as their only viable treatment option. The need for fairness in organ transplantation stems from the broader social responsibility of ensuring that all individuals are treated fairly, particularly in the healthcare system. Although this does not implicitly guarantee equality in life chances, it requires that if society has contributed to differential access to LDKT through policies that in effect limit the ability of certain vulnerable groups to find donors within their social network, then society has the responsibility to correct for that inequality and ensure fair access to treatment for all patients with renal failure. If, however, disparities in LDKT are truly the result of fully autonomous choices made by patients and their social networks, then distributive justice would not imply an obligation to correct these inequalities. If the inequalities are the product of an unjust social environment and not the result of fully autonomous choices of social networks, then distributive justice would imply obligations to correct for the disparities. This paper will demonstrate that social networks are not chosen, but are instead largely an endowment that affects health. By demonstrating that Blacks may have fewer able and willing donors among their networks due to institutional discrimination and harmful social and environmental exposures, among other factors, we argue that they ought not be held responsible for their inability to pursue LDKT. Insofar as unjust social forces have affected the composition and health of networks of particular vulnerable groups, and insofar as that leads to a differential lack of access to LDKT, then society must ensure that access to any kidney donation is equitable (as part of treating people fairly). Because

society bears some responsibility for health consequences influenced by avoidable, involuntary, and consistently discriminatory social forces, people suffering related health consequences are entitled to specific compensatory action from society for the fraction of their poor health resulting from social forces. I argue that, in particular, we ought to be concerned with previously neglected disparities in LDKT, specifically the fraction stemming from disparities in social networks because networks provide one pathway by which inequalities can be perpetuated throughout society and over time.

3.1.1 Introduction

Despite disproportionate need and greater benefit, African-American patients who embody over a third of the waiting list receive only 13% of living donor kidney transplants (LDKT) (UNOS). Should this inequality count as a morally objectionable disparity and should public policy address it? End-stage renal disease (ESRD) patients have two treatment options: waiting for a deceased-donor transplant (DDKT) or obtaining a LDKT. Patients able to draw upon both deceased and living donors can improve their chances of obtaining a transplant: pursuing DDKT by completing an evaluation and being waitlisted, while concurrently pursuing LDKT by drawing upon their social network. Patients for whom LDKT is not an option are forced to wait for a deceased-donor organ, reducing their access to available to life-saving treatment. Recently, as the scarcity and wait times for deceased-donor organs increase, patients are turning to living-donor kidney transplantation (LDKT) as their only viable treatment option. LDKT now accounts for nearly half of all renal transplants in the U.S. and is associated with superior outcomes compared to deceased-donor kidney transplantation (DDKT). Despite legislation and universal Medicare coverage for all patients with ESRD, significant racial disparities persist in both access to

transplantation and in post-transplant outcomes (Eckhoff et al., 2007; Ladin, Rodrigue, & Hanto, 2009; Weng, Reese, Mulgaonkar, & Patel, 2010). African-Americans with end-stage renal disease (ESRD) spend more time on dialysis, receive fewer and lower quality organs, have longer waits, experience higher rates of graft failure, and suffer higher mortality rates than their white counterparts (Eckhoff et al., 2007; Epstein et al., 2000). Of all disparities in transplantation, disparities in LDKT are most egregious.

Thus far, efforts to address disparities in transplantation and to achieve fairness in resource allocation have focused on individual-level factors, including: education, wealth, income, gender, race, occupational status, and even geography. Adjustment for individual characteristics stems from an attempt to compare like with like and from an effort to promote fair access to treatment. In this vein, the deceased-donor allocation algorithm has been revised continuously to improve equity in access to transplantation. Such efforts have reduced racial disparities in organ allocation (E. C. Hall et al., 2011). By contrast, efforts to increase equity in access to LDKT have been met with only mild success. This may be partly because focusing on individual-level factors alone does not adequately correct for disparities, and results in a residual disparity that can be deemed unfair (Ladin Paper 1). This residual disparity may be due in large part not to individual-level differences, but rather to differences in characteristics of their social networks (Ladin Paper 2).

Despite their potential contribution to LDKT disparities, efforts to mitigate disparities have excluded social networks. Medical criteria consistently discount the influence of social networks in an effort not to bias the decision-making. Indeed, medical professionals have long rejected the notion that medical resources should be allocated on the basis of a person's instrumental value to others or to society. Social networks have been neglected in resource allocation in an attempt to avoid nepotism and minimize the influence of social

status. Furthermore, others may object to inclusion of social networks as a factor due to lack of clarity surrounding the mechanisms by which networks affect health outcomes. Finally, there may be others reasons to object to including social networks among relevant considerations for resource allocation, namely because social networks are perceived to be a result of personal choices, and therefore a matter of personal responsibility.

Still, ignoring the impact of social networks on a patient's ability to pursue treatment is also problematic for a number of reasons. First, a patient's ability to pursue LDKT is heavily reliant upon the patient's social network, since their network encompasses their pool of potential donors. As such, disregarding the impact of networks on LDKT leaves a large residual disparity unexplained and unaddressed. Second, neglecting the role of social networks in predicting LDKT places significant responsibility and burden on the patient, a consequence that the patient may or may not be responsible for. Third, unlike DDKTs, which are obtained and allocated to waitlisted patients according to a formal priority algorithm, LDKTs are obtained through informal means, most often from a patient's social network (family, friends, coworkers, neighbors, etc.). Reliance on informal mechanisms and social networks places a significant onus on patients, in particular those who may have networks that are sicker, already strained, and less likely to undergo elective surgery. Compared to whites, black patients are less likely to have a potential donor evaluated, and less likely to obtain a LDKT even if potential donors are evaluated (Weng, Reese, Mulgaonkar, & Patel, 2010) Ladin paper 1, Ladin paper 2). Finally, having black patients bear a disproportionately high disease burden due to their social network's inability to donate is unfair because patients do not choose many features of their networks. Although some aspects of social networks are chosen, for example whom one befriends, social networks are largely dictated by parental choices and social determinants, and are rarely reflective of fully

autonomous choices. Taking social networks into account may require us to expand the set of factors that we deem to be morally relevant. Although in general, there may be good reasons that we ought to resist considering social networks in health care allocation decisions, in this case, these reasons are trumped by fundamental concerns about the social commitment to fair and equal treatment.

Intuitions about what distributive justice requires and the moral obligation to improve access to LDKT hinge upon whether disparities in LDKT are the result of fully autonomous choices made by patients and their social networks, or whether disparities are instead the product of an unjust social environment that perpetuates inequity by systematically influencing social networks.⁴ The legitimacy of claims to compensatory damages depends on the mechanism underlying the gap. Claims meriting special consideration to compensatory damages stem from circumstances that are more than merely unfortunate and unavoidable; they are avoidable and unjust. If the likelihood of receiving a life-saving kidney (from a deceased or living donor) was randomly distributed in the population, there might not be grounds for ethical concern because all patients would be equally likely (or unlikely) to receive an organ. In reality however, the likelihood of receiving a LDKT is unequal and is strongly correlated with many factors that underlie health disparities, such as race, financial status, cultural beliefs, and continuity of healthcare (Ladin, Rodrigue, & Hanto, 2009; Norris & Agodoa, 2005). By neglecting these disparities in LDKT, the likelihood of receiving a life-saving kidney is unfairly biased towards those most able to

⁴ Designating what is fully autonomous is admittedly difficult to classify. For example, if blacks internalize a stereotypically negative view of themselves and then make choices based upon this, it is difficult to decide whether we should consider that choice to be fully autonomous, or whether it is more strongly influenced by social forces.

draw upon an additional pool of resources to secure an organ, namely, members of their social network.⁵

By demonstrating that Blacks may have fewer able and willing donors among their networks due to institutional discrimination and harmful social and environmental exposures, among other factors, we argue that these patients ought not be held responsible for their inability to pursue LDKT. Insofar as unjust social forces have affected the composition and health of networks of particular vulnerable groups, and insofar as that leads to a differential lack of access to LDKT, then society must ensure that access to any kidney donation is equitable (as part of treating people fairly). We argue that, in particular, we ought to be concerned with previously neglected disparities in LDKT, specifically the fraction stemming from disparities in social networks because networks provide one pathway by which inequalities can be perpetuated throughout society and over time. Section 2 will define social networks and discuss the influence of networks on health. Section 3 will present the ethical arguments for mitigating disparities in LDKT. This section will demonstrate that numerous theories of distributive justice converge in suggesting that preserving health is important to achieving equality of opportunity; and that minimizing variation in health outcomes stemming from social forces is ethically desirable. Section 4 will review the evidence and mechanisms underlying disparities in LDKT, highlighting the role of social determinants and social networks. Section 5 will examine the libertarian objection and replies. Section 6 will discuss policy implications and Section 7 concludes.

3.2 Definition of Social networks, Endowments and Personal Choice

⁵ For the purposes of this paper we consider only the pools of organs legally available (via social networks), which means we do not consider purchasing organs or solicitation.

Obtaining a LDKT is a multi-step process. First, the patient must be evaluated and deemed a suitable for transplantation. Factors such as low socioeconomic status, older age, worse health, and minority race/ethnicity, and lack of private insurance have been associated with disparities in achieving this first step (Ayanian, Cleary, Weissman, & Epstein, 1999; E. J. Gordon, 2001; Siminoff, Burant, & Ibrahim, 2006). Second, the patient must have access to a medically suitable and willing living donor and must discuss LDKT with him or her. Third, the potential donor must ultimately be deemed psychologically and medically fit, and ideally ABO blood type compatible (although ABO incompatible LDKT are performed). Some live donors are HLA identical to the recipient and this confers immunological advantages and occurs much more frequently if they are related. Finally, conditional on finding a suitable donor, discussing LDKT, and having the donor agree to donate, the donation must actually take place (before any conditions that might change eligibility, such as donor or candidate illness). The likelihood of receiving a transplant, from living or deceased donors, is a function of both unchosen factors (we will call these factors endowments) and personal choice. Factors reflecting personal choice include willingness to undergo evaluation and willingness to pursue LDKT, in contrast to endowment factors that include blood type, sensitization, age, and race. Some factors, such as socioeconomic status, insurance and geography, may be influenced by both endowment⁶s and personal choice.

Social networks can affect all stages of the LDKT process. Social networks refer to the structure of social relationships, also called ties, and the connections between an individual and others with whom the individual interacts. Social networks can be characterized in different ways, including the availability of ties (number, proximity, and

⁶ In this paper, we will define endowments to mean to the innate capacities of an individual, which include both "natural endowments" (genetic abilities given at birth such as intelligence or strength), and "social endowments" (attributes linked to a relative position within a social hierarchy such as social mobility).

accessibility of ties), the structural characteristics of those ties (density, directionality, and other factors), the composition of ties (with kin versus nonkin, friendships, and ties gained through formal organizational linkages), and the efficacy of ties (the ability of ties to facilitate the transfer of resources). The size and structure of social networks can directly affect a patient's ability to obtain a living donor kidney. A larger network, one with more ties, may afford the patient more opportunities to find a willing and able donor, whereas a small network, or at the extreme a person lacking any network, may never find a donor. The composition of the network matters as well. For example, having more kinship ties may improve chances of LDKT by increasing the probability of a genetic match. Other network characteristics, like density, strength of ties, and health of network members, among others, may also be predictive of LKDT. Network composition may also be important in that having a more diverse or open network may allow a patient to draw upon a diverse set of resources, may be beneficial for information diffusion (Granovetter, 1973).

Some may want to exclude networks from the set of relevant criteria that would afford an individual special claims or additional priority to transplants on the grounds that networks are a function of personal choice. Although *prima facie*, it may seem that people have much control and choice over the size and composition of their social networks, in reality many features of networks not chosen and not easily malleable, and so appropriately count as endowments. For example, network size and composition are, to a large extent, an endowment⁷. Kinship associations are based largely on decisions made by one's parents, grandparents, aunts or uncles. These decisions determine the number of siblings or cousins,

⁷ We can address disadvantages that result from endowments in different ways. A luck egalitarian may view any unchosen disadvantage as something that merits compensation. Rawls, however, treats the talents and skills an individual has by the natural lottery not through a principle of redress but through the Difference Principle, on the assumption that someone is likely to be at a lower place on the index of primary social goods as a result of marketable talents and skills, so this is a mitigation of the effects of endowment, but not a compensation (redress) of them. So for Rawls, some issues of endowment are not addressed like others (we cannot discriminate on the basis of race or sex but we can assign people to jobs based on talents and skills).

and even the degree to which one knows his/her family, as this often depends on upbringing and continuous exposure to family. The ability to meet others and form strong bonds, although partly influenced by personal choice, is also strongly affected by the built environment and other social determinants. Networks are affected by choices about where families live and by social structures, illustrating the contribution of two factors: social forces and the influences of outside individual and parents. Residential environments, schools, and workplaces can foster or impede the development of strong bonds (Kawachi & Berkman, 2003; Pearce & Davey-Smith, 2003). Poorer environments often lack safe, common spaces and often have lower levels of social capital, both important factors for social networks. The ability to move to a different environment that might afford higher social capital and foster a social network is often limited by social determinants, such as the potential for upward mobility and economic and class-based constraints.

Furthermore, even if networks of black and white patients were equally willing to donate, there might be differences in their ability to donate. This notion is supported by evidence that certain health characteristics, like obesity, smoking, and other precursors to kidney disease, can spread through networks. The literature on social determinants suggests that these risks also track with poverty, residential segregation, low socioeconomic status, and black race (Axelrod et al.; Ladin, Rodrigue, & Hanto, 2009). If networks of black patients share health risks, and these health risks preclude them from donation (since these are contra-indications to donation), then we have additional grounds to be concerned with the effect of networks on disparities in LDKT. Taking into consideration that networks are shaped by a combination of personal choices and endowments, it is clear that we cannot necessarily hold people responsible for the poor health outcomes resulting from their social networks.

3.3 Ethical basis for protecting health and minimizing health disparities

If in fact some groups have fewer chances to pursue LDKT because their social networks are unable or unwilling to donate, does it matter whether the disparity is a result of personal choice or endowments? There is rather cause for concern if unjust social forces influence endowments in such a way that systematically restricts equal access to treatment of a particular vulnerable group. Insofar as these forces limit the size or scope of a social network therefore limiting available social resources, we have grounds to be concerned with their effect. For example, although family size is often considered a random endowment, if a policy existed where family size was limited (e.g. a one child policy) and only people with financial means could afford to expand their family size beyond that, we might have additional grounds to be concerned with the implications of small family size. In the case of LDKT disparities, the moral relevance of this distinction lies in the contrast between risks that we might hold individuals responsible for and consequences that we should not hold them responsible for. The fact that social networks are themselves largely unchosen endowments might not be enough to compel compensatory action. Although a luck egalitarian may view any unchosen disadvantage as something that requires compensation, I would view this as a necessary although not sufficient condition for two reasons. First, taking into account that all kidney disease is unchosen, and as a result, any patient with ESRD has legitimate claims to treatment, it is not clear that the unchosen nature of the disease confers any additional priority over other patients with similar needs. Second, if the risk of finding a willing and able donor was randomly distributed among ESRD patients, then perhaps no single patient or set of patients would have claims for special consideration on the grounds that there is no injustice and that taking their situation into account might

unfairly disadvantage another patient. However, LDKT disparities are not just unchosen, they also causally track with broader social and health disparities, suggesting that a group of patients systematically faces fewer treatment options, in part, due to the influence of unjust social forces. The sufficient condition in this case is the impact of social forces on unequal access to treatment through their influence on social networks. I argue that if society has contributed to differential access to LDKT by restricting the ability of certain vulnerable groups to find donors within their social network, then society has the responsibility to correct for that inequality and ensure fair access to treatment for all patients with renal failure.

The view that society ought to be concerned with disparities stemming from factors that are unchosen, unavoidable, and unjust is grounded in the Whitehead-Dahlgren ethical framework for understanding health disparities. Many inequalities are considered tolerable or acceptable by social standards, underscoring the importance of the distinction between 'difference' and 'disparity', scholars have used the term “difference” to mean unavoidable, consistent, and measurable variation in health outcomes. These health gaps, although potentially of import to society, do not result from unjust social forces and therefore do not merit special consideration on these grounds.^{8,9} Conversely, disparities can be defined as differences which are “unnecessary and avoidable, but in addition are considered unfair and unjust” (Whitehead 1992). Health disparities stemming from the basic structure of society

⁸ Longer life expectancy among American women compared to men might be an example of a difference that is not a disparity. Women are still often subject to social discrimination, and yet, on this dimension of health, they appear to be better off than their male counterparts. However, lower life expectancy among minorities (African-Americans) can be considered to be a health disparity. Higher rates of violent death, less access to health care, stress, and poor environmental conditions all appear to contribute significantly to this gap, and as a result, it is considered to be a disparity.

⁹ We may have obligations of justice to reduce “differences”—e.g. if a genetic disorder is not the result of social factors, and is unavoidable in its onset, it may still be treatable, and we may have obligations (resources permitting) to treat the resulting health inequalities (or differences).

(gender, class, race, etc.) or resultant from the social division of labor benefiting the advantaged at the expense of the disadvantaged are often deemed to be unjust or unfair. Deeming a gap in health outcomes to be a disparity requires some knowledge of the mechanism by which this gap arose and through which it is perpetuated, along with evidence that the gap is derived, in part, from social forces. In this section, we examine the factors that have led to disparities in LDKT, and the role of social networks in perpetuating these disparities in an effort to conclude whether gaps in LDKT stemming from differences in social networks are morally concerning.

Although not explicitly rooted in theories of distributive justice, numerous approaches to distributive justice are concerned with the fair distribution of opportunity and advantage. Scholars have made connections between protecting health and protecting the functional opportunity range, wellbeing, primary goods, and capabilities. Advocating a capabilities approach, Sen concludes that “any conception of social justice that accepts the need for a fair distribution as well as efficient formation of human capabilities cannot ignore the role of health in human life and the opportunities that persons, respectively, have to achieve good health – free from escapable illness, avoidable afflictions and premature mortality (Sen 2002: 660)”. Sen distinguishes between equality of achievement and capability, and the resources socially available for that achievement (Sen, 2002). Preserving the importance of personal choice, Sen establishes capabilities as an individual’s opportunity and ability to generate valuable outcomes (e.g. leading a full and healthy life), accounting for relevant personal characteristics and contextual factors (e.g, unjust social inequality). Sen’s focus on preserving equality in the freedom to achieve provides a basis for concern with social inequalities that may constrain an individual’s ability to achieve the entirety of their capability set, restricting their choice and reality to a limited subset (Sen, 1979). Sen also

reaffirms the importance of fair societal distribution of health for preserving social justice. Incorporating empirical findings demonstrating the effect of social determinants on health, Sen concludes that, “to argue for health equity cannot just be a demand about how health care, in particular, should be distributed... The factors that can contribute to health achievements and failures go well beyond health care, and include many influences of very different kinds, varying from genetic propensities, individual incomes, food habits and life styles, on the one hand, to the epidemiological environment and work condition, on the other” (Sen, 2002).

Extending Rawls’s theory of justice as fairness to include health, Daniels argues that preserving health is intrinsic to preserving equality of opportunity because health is instrumental to making and revising life plans (Daniels, 1985). Insofar as it is important to protect health (by protecting health needs) in order to maintain equality of opportunity, and since Rawls’s Justice as Fairness requires protection of opportunity (as do other important approaches to distributive justice), then several recent accounts of justice give special importance to meeting health needs (Daniels, 2008). (Daniels, 1985; Daniels, Kennedy, & Kawachi, 1999; Rawls, 1971). Moreover, Daniels argues that protecting normal functioning, (e.g. reducing or mitigating deviations that stray from normal species functioning in a way that cause harm or result in deficiency or illness) is important because of its tendency to “promote happiness or the satisfaction of preferences”, and to protect “exercisable opportunities open to individuals from which they may construct their ‘plans of life’ or ‘conceptions of the good’” (Daniels 2008: 35).

Both Sen and Daniels emphasize the importance of addressing inequalities stemming from social forces that unfairly impede the capabilities or opportunities of vulnerable populations to achieve good health. Luck egalitarians, such as Arneson, argue similarly that,

though inequality may be undesirable in and of itself, it is far worse when it befalls someone who is undeserving of being made worse off. This suggests that “the badness of inequality is lessened, the more it is the case that the relative level of good fortune that people reach is proportionate to their desert”, and when it befalls someone in a manner that is involuntary, meaning that “the badness of inequality is lessened, the more it is the case that inequality arises via people’s voluntary choices within a fair framework for interaction” (Arneson, 2004).

While these views of distributive justice diverge in many ways with respect to the underlying motivation for protecting health and the scope of protection, they converge in suggesting that health is essential for making and revising life plans, and that reducing health disparities is central to achieving equity and fairness. These theories demonstrate that an unbalanced distribution of health resources (in this case organs) resulting in unequal life chances is ethically problematic. These theories all suggest that at some level, society is responsible for health consequences determined by avoidable, unchosen, and consistently discriminatory social forces. People suffering health consequences resulting from social determinants are entitled to some remuneration from society for the fraction of their poor health that was influenced by social forces. Insofar as disparities LDKT embody a specific disparity in health, there are compelling ethical grounds to be concerned them as well.

3.4 Determinants of Disparities in LDKT

Given that we have grounds to be concerned with health disparities that are unnecessary, avoidable, and unjust, and given that social networks provide one mechanism by which social forces perpetuate social inequality and unequal access to treatment, then we have grounds to be concerned with disparities in LDKT. Although there are have grounds to

be concerned with such disparities, what is the evidence that disparities in LDKT are, in fact, associated with social networks and that these, in turn, have been influenced by social forces? This section reviews the evidence for disparities in LDKT, in particular, whether social networks may be responsible for racial disparities in LDKT.

3.4.1 Disparities in LDKT: Individual and health care system determinants

Although this paper is concerned primarily with disparities resulting from social networks, we first briefly review the influence of individual-level factors on disparities in LDKT since that has been the focus of the literature thus far. Despite universal Medicare coverage, individual-level sociodemographic factors contribute to disparities in treatment. There is ample evidence that black patients suffer delays and lower quality treatment due to socially determined risk factors such as financial status, unemployment, incomplete workups and lack of continuous access to care (Epstein et al., 2000). Among patients desiring a transplant and approved for surgery, African-American race, lower income, and lower educational attainment were associated with lower odds of LDKT (Gore, Danovitch, Litwin, Pham, & Singer, 2009). Reese et al. (2009) found that younger candidates and those with higher yearly incomes were more likely to have a potential donor evaluated, and whites were more than twice as likely as blacks to have had a potential donor evaluated (Reese et al., 2009).¹⁰

Provider and center-level factors have also been associated with persistent disparities. Numerous studies have documented physician bias (often subconscious) in decision making, particularly when evaluating patients of low SES, low literacy rates, higher age and racial and ethnic minorities (Ayanian et al., 2004). Studies demonstrate that physician behavior often

¹⁰ One partial explanation stems from the disproportionate need among African Americans for financial assistance to overcome costs associated with LDKT (Boulware, Troll, Plantinga, & Powe, 2008).

mirrors their beliefs that minority patients are reluctant to pursue transplantation, prefer dialysis, or are less likely to benefit from transplantation (Robinson, Joffe, Pisoni, Port, & Feldman, 2006; Wolfe et al., 1999). Insufficient time and resources for culturally-sensitive education about transplantation also contribute to disparities (Beasley, Hull, & Rosenthal, 1997) . A recent study concluded that none of the transplant centers in the U.S. exhibited racial parity in rates of LDKT. African Americans experienced 35% lower odds of LDKT at centers with the least disparity compared to 76% lower odds at centers with the greatest disparity. Centers with higher percentages of African American candidates had higher racial disparity (E. Hall et al., 2012).

3.4.2 Network-level factors

Although individual risk factors and provider/center characteristics contribute demonstrably to disparities in LDKT, these characteristics account for less than a quarter of the overall variation in LDKT rates (Gore, Danovitch, Litwin, Pham, & Singer, 2009). In fact, a recent study estimates that even accounting for medical, sociodemographic, and some familial characteristics does not account for the gap in LDKT between whites and blacks. (Ladin Paper 1). Social networks have been shown to influence health outcomes through various pathways, including shared social capital; similar, group risky behaviors; shared social norms and transmission of pathogens or disease (Smith & Christakis, 2008). LDKT is especially susceptible to the effects of social networks because in this case the patient's ability to pursue treatment is directly related to his or her social network.

3.4.3 The Influence of Social Networks on LDKT Disparities

What mechanisms might explain the influence of social networks on LDKT disparities? Is there evidence that disparities in LDKT are, in fact, associated with social networks and that these, in turn, have been influenced by social forces? This section proposes four main pathways by which social networks might influence LDKT disparities. First, the *size and composition* of the network influence how many potential donors are available. Differences in network size, strength, or composition disadvantage patients whose networks are smaller, weaker, or who are genetically linked to fewer people. Second, the *willingness of patients to approach* their friends and family about donation may vary. Cultural norms and distrust of healthcare providers may also be reinforced through networks, suggesting that minority networks may have higher levels of distrust. Third, upon being informed about the option, the *potential donor's willingness* to undergo an evaluation may also vary systematically between networks. Finally, even among potential donors willing to proceed with donation, *poor health and unhealthy behaviors reinforced through networks* may disadvantage minority patients further as their social contacts may be unfit for donation.

Insofar as social determinants impact life chances by constraining a patient's ability to obtain a LDKT, and insofar as social networks are the mechanism by which these social determinants disproportionately influence the health of a vulnerable group, then we should be concerned about the impact of social networks on health. This section examines how networks adversely affect the ability of black patients to obtain a LDKT, and considers whether social forces influence the risk factors and are therefore morally relevant. This section will highlight that many features of networks are both unchosen and influenced by unjust social forces in a way that systematically disadvantages blacks.

3.4.4 Differences in the size or strength of networks

Exclusionary policies that create and sustain poverty, including residential segregation, contribute to the formation of smaller and weaker social networks. These admittedly unjust policies thus create the sufficient condition noted earlier. Network size and composition affect the pool of potential donors and are largely influenced by endowments. Family structure, in particular, is an endowment that may strongly influence LDKT by affecting genetic compatibility and closeness of ties. Since the 1960s, marriage rates have declined in the United States (Taylor, 2010), most precipitously among blacks.¹¹ Black children are nearly three times as likely as white children and nearly twice as likely as Hispanic children to live with one parent. Multiple-partner fertility and complex family structures have also become more common among Blacks, especially those of low socioeconomic status, black men with a history of incarceration, and black parents who had children at a young age (Cancian, Meyer, & Cook, 2011). Blacks are less likely to have full-siblings and more likely to have half-siblings than their white counterparts. Although causes for the change in family and marital structure among blacks in the United States are multifactorial, social policies have played a significant role. These policies include the tremendous increase in incarceration rates of African-American men of marrying age (Banks, 2011; Justice, 2008; Moynihan, 1965). Paid employment and educational attainment create different opportunities and constraints for association and friendship, and have been strongly and positively correlated with network sizes and ties to nonkin (Fischer & Olicker, 1983; Marsden, 1987; Moore, 1990). Differences in the structure of kinship ties and in genetic compatibility (potentially due to fewer full siblings, greater genetic diversity, and higher transfusion rates) may explain a smaller pool of suitable potential donors for black patients (Angel & Tienda, 1982; P. N. Cohen & Casper, 2002; Marsh, Darity, Cohen, Casper,

¹¹ Blacks (32%) are much less likely than whites (56%) to be married, and this gap has increased significantly over time.

& Salters, 2007) 1984). Although family structure and personal ties may be influenced by a combination of personal choices and endowments, the patient in need of a kidney has had no choice over the circumstances of their birth and upbringing, including their family structure.

Residential segregation, differences in incarceration and crime rates, and variation in social capital limit the ability of black patients to find suitable donors among their social networks by influencing the size and health of their network. Several scholars have argued that neighborhood conditions influence the size and composition of social networks (Small; Wilson 1987, 1996; Sampson, Morenoff, and Earls, 1999, others?), and that these neighborhood conditions partly explain racial differences in social networks (Sampson, Morenoff, Gannon-Rowley, 2002). In particular, the high concentration of poor blacks in urban areas perpetuates social isolation, lessening the probability of contact with people who are employed, not poor, and educated (Wilson 1987, 1996). If blacks have little ability to emerge from these environments into which they may be born, and if social determinants adversely impact the networks of blacks by limiting their ability to form strong, stable networks that would facilitate social support and upward mobility, then we have grounds to be concerned with the effects of residential segregation on LDKT disparities since these would limit . Residential environments also influence network size and composition and are affected by personal preferences and societal constraints, such as affordability and availability of housing, among other factors. While for many preferences prove to be the most influential factor, for vulnerable groups, endowments dictate housing options. The character of the local areas in which they live affects the formation of networks. Increasing concentration of income and wealth (and with it resources such as schools, parks, and public services) in a small number of neighborhoods has resulted in important nonrandom

influence of social determinants on the size and composition of networks (Reardon & Bischoff, 2011). Though living in a poor urban environment may be partly due to chance, social forces like gentrification, high housing prices outside the city, and discriminatory lending practices often play a significant role. These environments¹² are associated with lower levels of social capital, higher stress levels, and harmful environmental exposures (Cattell, 2001; Kawachi, Kim, Coutts, & Subramanian, 2004). Despite exposure to more people in an urban versus a rural area, various socially constructed barriers pose obstacles to achieving a large network. High levels of crime, lack of common spaces, and low social capital may lead to an inability to connect with such neighbors and form meaningful relationships (Morenoff, Sampson, & Raudenbush, 2001). Areas with high poverty rates, high levels of unpaid work, and low levels of home ownership are associated with smaller networks of nonkin ties (Small, 2007). Conversely, being born into or living in a suburban area where it is safe and common to develop relationships with neighbors may avail one to a larger pool of potential connections.

Blacks have been found to have fewer ties outside the family, smaller networks, particularly those offering social support or affecting social mobility (Marsden, 1987; Small, 2007). Blacks living in poor neighborhoods had relatively small and dense social networks (Klinenberg, 2002; Small, 2007). Importantly, recent work by Small suggests that it is poverty, not the racial composition of neighborhoods that is significantly associated with weaker social ties, underlying the effect of social determinants on networks (Small, 2007). In his research following poor tenants who were evicted from their homes, Desmond found that tenants often relied on relatives for some assistance; however they met many obstacles when seeking assistance from kin. Therefore to meet their most urgent needs, evicted

¹² Some debate about whether living in an urban vs suburban environment is a choice. Arguably, for many it is not. Discuss gentrification, lack of housing choices due to limited income and limited social mobility.

tenants relied heavily on “disposable” ties formed with new acquaintances over more established ties of reliable kin. Desmond suggests that although evicted tenants formed intimate ties rapidly, “these bonds often were brittle and fleeting, lasting only for short bursts. This strategy of forming, using, and burning disposable ties allowed families caught in a desperate situation to make it from one day to the next, but it also bred instability and fostered misgivings between peers” (Desmond, 2012).

While endowments comprise one aspect of social network size and composition, preferences may also play a role. Although some people may inherit a small network, others (e.g. people who are shy or hermits) may have preferences to avoid social contact and therefore have a very small network. Differences in network size, therefore, can be attributed to *dispositions* of people as well as to *social structure*. These two perspectives, the dispositional and structural, allow us to better understand the causes and moral relevance of network differences. For example, although there are no differences in network size by gender, women tend to have denser networks comprised of mostly kin with few ties to people in positions of power, compared to men who benefit from diverse and extensive networks of colleagues (Ibarra, 1993, , 1995). The dispositions perspective suggests that gender differences in social networks result from women being more *disposed* to maintaining closer relationships with kin and fewer or weaker ties outside the family (Moore, 1990). Conversely, the *structural* perspective suggests that structural barriers such as unequal labor force participation and discrimination in promotion of women accounts for these differences. Though dispositional differences exist, social networks depend far more on opportunities for social contact (Blau, 1977): 281). As such, a large fraction of size and structural differences are endowments that are socially influenced.

3.4.5 Differences in willingness of patients to ask and of social networks to donate

Differences in the size and composition of networks dictate the pool of potential donors available. However, realizing the potential of the pool of donors depends on the willingness of the transplant candidate to approach their network members, as well as the eventual willingness of their network members to pursue and complete a transplant evaluation, and ultimately undergo surgery. Research demonstrates that many candidates do not approach anyone, and most candidates who do have two or fewer potential donors evaluated (Weng, Reese, Mulgaonkar, & Patel, 2010). Others, who do have friends and family offer to donate, often refuse offers largely due to concerns about the burden and health risks to the donor (Barnieh et al., 2011; Zimmerman, Albert, Llewellyn-Thomas, & Hawker, 2006). Potential candidates overwhelmingly underexplore their social networks when seeking LDKT, and black candidates utilize their networks far less than whites. Various social factors influence dispositions to make use of networks. First, high levels of medical mistrust stemming from either actual or perceived discrimination may negate a person's willingness to ask loved ones to donate, and also affect willingness of potential donors to consider elective surgery. Second, lack of continued access to health care may provide a significant barrier for potential donors. Third, greater job instability and greater financial needs also contribute substantially to disparities in willingness to donate. Finally, racial differences in the medical consequences of donation may reduce the willingness of blacks to request or agree to donation. We briefly examine whether these causes are a function of personal choice or endowment, and whether they have been influenced by social determinants. If racial differences in willingness to ask for or to donate an organ are a

function of endowments and unjust social forces and not merely personal choice, this provides further grounds for ethical concerns about LDKT disparities.

Black patients may be less willing to approach their social network members and request donations due to greater mistrust and suspicion about medical system. Studies have demonstrated that black patients have higher levels of medical mistrust (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Smedley, Stith, & Nelson, 2003). Likely in part a result of historical abuse, Black patients report being more concerned about personal privacy and potential for harmful experimentation in hospitals, factors that could deter them from asking their loved ones to undergo elective surgery. Medical mistrust can be considered an endowment, stemming from a long history of poor treatment and discrimination (Gamble, 1997; Jacobs, Rolle, Ferrans, Whitaker, & Warnecke, 2006). Even post-slavery, during the decades of segregation, racism and discrimination were pervasive in the health care system. As a consequence of the Supreme Court's decision in "Plessy v. Ferguson" (1896) upholding the constitutionality of state laws requiring separate but equal facilities, Blacks were excluded from medical schools, restricting the number of Black doctors. During the Jim Crow era, they were also excluded from many facilities treating white patients, and as a result could only seek care reliably at black medical facilities or in segregated units in some hospitals. Blacks were also used as unknowing participants in medical experiments, perhaps most egregiously in the Tuskegee Syphilis Study, which infected Black men with syphilis and denied participants treatment for forty years (Gamble, 1997). With the passage of the Civil Rights Act (1964), federally funded programs were prohibited from discriminating on the basis of race, eventually leading to racial integration in medical facilities.

Against this backdrop of discrimination, the reasons for greater medical mistrust among Blacks are clear. Although access to health care and overt discrimination has

decreased since the 1960s, disparities in access to and quality of care persist. Specifically related to transplantation, Blacks are less likely to discuss transplantation with physicians compared to whites, and even when Black patients reported a desire for transplantation, in nearly a third of cases physicians did not have a discussion about LDKT with their black patients (Ayanian, Cleary, Weissman, & Epstein, 1999). Reasons for suboptimal patient-physician discussion include patients' distrust of physicians or fear of surgical procedures and patients' subsequent reluctance to ask about new therapeutic options, physicians' assumptions that patients are not interested in transplantation and patients' or physicians' perceptions that patients are not medically suitable for LDKT (Ayanian et al., 2004; Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Epstein et al., 2000; Figaro, Russo, & Allegrante, 2004; E. J. Gordon, 2001). In one study, over a third of nephrologists perceived poor patient-physician communication or trust to be a contributor to ethnic/race disparities. In a recent study, when asked whether they need more information to make an informed decision about LDKT, black patients were more likely to report needing more information (Ladin Paper 2).

Once asked, are there disparities in people's willingness to donate? Likelihood of donating may depend on individual preferences, risk threshold, and pain tolerance, amongst many other factors. It may depend also on the potential donor's relationship with the transplant candidate: their degree of closeness, perhaps the length of time that they have been acquainted, the strength of their ties, and perhaps the nature of their relationship (spouse, kin, friend, coworker). It may also be influenced by a potential donor's view of justice or religion, whether they feel a calling or moral obligation to help save a loved one, and whether they believe that their ability to aid is accompanied by a moral obligation to do so. These features of people may vary arbitrarily, in some part due to endowments: due to

unique personalities that are inherent to one's nature and the social connections and roles inherited upon birth. While nature may play a large role, social determinants may be equally significant in determining our willingness to donate an organ.

A significant literature has documented higher levels of medical mistrust among blacks in the United States, stemming from a history of discrimination in medical treatment and unethical experimentation (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). As a result, medical distrust is higher not only amongst black patients, but also amongst potential donors of black transplant candidates, suggesting that these social networks may be less likely to donate, even if approached (Ladin Paper 2). One study found that mistrust in hospitals and concerns about discrimination were independently associated with 50 to 60 percent lower odds of willingness to donate. Such deeply entrenched medical mistrust is not a matter of personal choice, but rather an endowment that is embedded in the nefarious history of racism in the U.S. Concerns about surgery have also contributed significantly (Boulware, Ratner, Cooper et al., 2002; Boulware, Ratner, Sosa et al., 2002; McCann et al., 2005). For example, a disproportionate number of cancer deaths occur among African Americans, who have a 33% increased risk of dying of cancer compared with whites (Shavers & Brown, 2002). This is in large part because African-Americans are less likely to receive received appropriate surgical resection, particularly for lung and colorectal cancers. In many cases, racial/ethnic disparities in treatment were not explained by differences in clinical profiles.

Lack of continued access to health care also poses a significant barrier to living donation, particularly for minorities who are uninsured at much higher rates than whites (Gore, Danovitch, Litwin, Pham, & Singer, 2009; Isaacs et al., 1999; Lentine et al., 2010). Although donation is covered by the recipient's insurance, higher rates of comorbidities

several years after surgery combined with a higher risk of uninsurance could serve as a significant deterrent. Lack of continued access can also exacerbate medical mistrust, jointly reducing the likelihood that social network members of black patients will donate. Other social determinants such as low income, greater job instability, and greater financial needs further reduce the willingness and ability of minorities to donate. Social network members of black patients resemble them in many of these characteristics (homophily). A recent study shows that network members of black patients have much lower incomes than whites, have lower levels of educational attainment, and a weaker financial safety net (Ladin paper 2). Their social safety nets are also more strained, due to a large number of dependents and limited resources. As a result, black patients are far less likely to find willing potential donors among their social networks due to causes that are partly socially determined, and in no small part endowments.

Finally, although there may be many differences in perception of risk associated with donation, actual risk differences may help explain racial disparities in LDKT. The most comprehensive follow-up study examining health outcomes of living donors found that after kidney donation, black donors, as compared with white donors, had an increased risk of hypertension, diabetes mellitus requiring drug therapy, and chronic kidney disease; findings were similar for Hispanic donors (Lentine et al., 2010). ESRD was identified in less than 1% of donors but was more common among black donors than among white donors. Black donors might be at higher risk for uninsurance following transplantation and may have greater difficulty paying for needed medical care. These findings, however preliminary, may reflect a real difference by race in health and financial risk for donors following donation. The greater burden on Black donors could decrease the willingness of black patients to

request an organ from loved ones, and could also decrease willingness to donate among the black population.

3.4.6 Differences in ability to donate

Assuming that black and white patients were equally likely to approach their network members to ask for donation, and even assuming that potential donors (regardless of race) would be equally willing to pursue donation, a final hurdle remains. The potential donor must be medically suitable in order to undergo transplantation. Donors must be sufficiently healthy to donate and must be genetically compatible with the recipient. This poses two challenges to black donors (Lunsford et al., 2007; Reeves-Daniel et al., 2009). Race is strongly associated with family structure, which may influence the genetic compatibility and availability of potential donors.

Importantly, social networks of black patients may be in poorer health than social networks of white patients. Many health outcomes and behaviors, such as obesity, depression, and smoking have been shown to spread in social networks (Smith & Christakis, 2008). A recent study suggests that social networks of black patients are more likely to be obese, diabetic, and report being in poorer health than those of white patients (Ladin Paper 2). Several of these factors (obesity, diabetes, hypertension, and chronic kidney disease) are contra-indications to donation, suggesting that even if are willing to become donors, the likelihood that they will be medically eligible is quite low. Other studies have found similar results among the black population at large. On the population-level, blacks are more likely to suffer morbidities that would make them contra-indicated as donors. These conditions include (but are not limited to) obesity, diabetes, hypertension, kidney disease, and psychiatric conditions (Baker & Bell, 1999; Herz, Unger, Cornell, & Saunders, 2005; Mokdad

et al., 2003). Given that people's networks often resemble them, both in terms of their racial, socioeconomic, and even health characteristics, it is less likely that black ESRD patients will find eligible donors among their networks than white ESRD patients.

In summary, in the case of LDKT, these differences in networks play an even larger role as they determine, in large part, the available pool of social resources and potential life-saving organs. Differences in the size and composition of social networks can have a significant effect on equality of opportunity, health, and access to LDKT. Differences in willingness to approach potential donors and willingness to donate also vary by race. Finally, conditional upon being asked and wanting to donate, differences in the ability of black potential donors might vary due to their poorer health. The racial variation between networks may be due, in part, to cultural norms and patient preferences to which no moral relevance is ascribed. Networks size and composition, patient willingness to ask their loved ones to undergo a nephrectomy and the willingness of black potential donors are strongly influenced by lower levels of trust in the medical system, greater burden among their social network to cope with adverse outcomes, and greater actual risk of adverse outcomes among minority donors (E.J. Gordon, 2001; Rodrigue, Cornell, Kaplan, & Howard, 2008a). Some elements of networks are based on preferences, while others are not chosen and not malleable. Insofar as the availability of potential donors is influenced, *in large part* by unjust social forces, we should be concerned with the fraction of LDKT disparities associated with those discriminatory forces.

Taken together, we can deduce that a considerable fraction of disparities in LDKT is associated with broader health and social disparities already deemed to be unjust and unfair.

3.5 Objections and Replies

3.5.1 Considering a Libertarian Objection

One objection to our concern with disparities in LDKT stems from a libertarian objection, which is as follows: if people are entitled to dispose of resources which they have justly acquired, doesn't this include their being entitled to donate an organ to whomever they want? Along this vein, given the natural right of individuals to own property and to their bodies, any subsequent distribution of organs (or LDKTs) must be just if it arises from voluntarily decisions to donate a kidney to another person, whatever the reason.¹³ Even assuming that the justice of the initial situation is patterned by an egalitarian principle, using his famous Wilt Chamberlain example Nozick argues that any distribution resulting from the voluntary and informed decisions of individuals to give personal possessions to others is just by virtue of transactional justice (Nozick, 1974). As such, Nozick presents a strong case for dismissing the concern with racial disparities in LDKT as morally irrelevant. After all, if the distribution of LDKT is unbalanced by race but arises from voluntary transactions between willing parties, what justification is there for governmental interference?

Without autonomy or voluntariness, any step taken to redistribute labor or the product of labor (in this case organs) is unjust. The same logic applies for any transaction involving an exchange of labor, the products of labor, or that which creates labor, namely the body. This underscores a problem with constraining an individual's right to donate to the person or group he chooses while further undermining the general concern with disparities in the distribution of organs. Restricting autonomy may be especially problematic in the case of organ donation where donor autonomy is paramount to ensuring justice in transplantation and protecting the donor's liberty. Without absolute voluntariness in the

¹³ For our purposes, we will only consider voluntary gifting of organs and not transactions involving sale or barter. A significant literature exists related to commodification (for a review, see (Goodwin, 2004). For arguments supporting commodification in altruistic donation, see de Castro. For additional considerations, see (Wilkinson & Garrard, 1996) and (de Castro, 2003)).

donation decision, coercion will corrupt the donation process and erode fairness and public trust in the organ transplant system. While forcing an individual to engage in a transaction against his will is clearly unjust, is the same true about choosing with whom to transact?

Are there grounds to constrain the scope of giving, in our case, donating kidneys? Nozick suggests that the existence of reasons and motives are important to the concept of transactional justice, and in their absence, we would find it disturbing were people to irrationally or arbitrarily engage in transactions without clear motives or belief of benefits. He emphasizes that, "This does not mean necessarily that all deserve what holdings they receive. It means only that there is a purpose or point to someone's transferring a holding to one person rather than to another, that usually we can see what the transferer thinks he's gaining, what cause he thinks he's serving, what goals he thinks he's helping to achieve, and so forth." (p. 159) In responding to Nozick, Cohen artfully points out that we clearly ought to be disturbed in a case where it is apparent what an agent engaging in a transaction hopes to gain, and it is also apparent that the agent will gain something less or that the agent will gain what she expects but also suffer unexpected consequences. (p.9) (G. A. Cohen, 1977). In revealing that full information and clear motives are central to preserving the transactional justice that results from a person freely giving or receiving something from another, Cohen unearths a significant crack in the foundation of Nozick's approach, and its application to disparities in LDKT. To be just, all concerned parties must willingly agree to the transaction with full knowledge and understanding of the subsequent consequences of their actions. Relying on Nozick's own Wilt Chamberlain example in which the famous basketball player becomes rich because many people are willing to give him a small sum, twenty-five cents, to watch him play, Cohen notes that some people (perhaps even a majority) would not have paid Chamberlain had they known in advance that their payment would result in giving him

unprecedented power. The “unacceptable amount of power over others” is an unforeseen consequence. In reflecting upon their decision to attend a basketball game, spectators should have weighed the utility of watching Chamberlain play against the disutility stemming from not only the monetary price, but also from the social division resulting from Chamberlain acquiring a large sum of money. Perhaps most importantly, Cohen notes that, “In presenting the Chamberlain fable Nozick ignores the commitment people may have to living in a society of a particular kind and the rhetorical power of the illustration depends on that omission” (p.11).

Cohen’s objection to Nozick maintains a significant role for the entitlement principle of justice in holdings, but leaves room for constraining the scope of gift giving in situations where not all parties have complete information, or where not all affected parties are privy to the decision-making. It also proposes at least one set of circumstances under which we should constrain people’s ability to give organs. Cohen argues that we should restrict transactions that result in the accumulation of excessive power within a certain person or group that threatens fundamental social values, even if it is at the cost of restricting individual liberty. Cohen notes that people may have a deep commitment to living and preserving a society with particular values, such as equality of opportunity, where people are treated fairly. In our case, both the public and transplant community are deeply vested in maintaining fairness and transparency in the transplant system. Organ allocation policies currently in place reflect this interest and are guided by the need to balance equity and efficiency. Given that social network disparities were unknown at the time the policies were developed, the public and transplant community have historically promoted fairness in renal allocation by ensuring that deceased-donor kidneys are allocated based on wait time, and outside of that, all patients can petition their friends and family for help. However, new

evidence suggests that living donation exacerbates disparities in transplants. As such, in donating to a particular person or group, the donor must weigh the benefits of potentially saving the life and bettering the position of a particular person or group, with the disutility not only of the surgery and potential post-operative complications, against the disutility stemming from heightened social divisions rooted in an unequal distribution of such life-saving resources and erosion of public trust in the fairness of the transplant system. Given overwhelming public support for a transplant system in which all patients waiting for organs are treated fairly, it is likely that the transacting parties would agree with this sentiment. Most importantly, Cohen's objection to Nozick gives us grounds to be concerned with disparities in LDKT, even if they arise from voluntary actions between two parties.

What should happen if, even knowing the potential for disparities, the donor still wants to donate? Given that there are strong reasons to allow directed donation to loved ones even if it results in disparities, (namely the benefit to the donor in keeping their loved one alive and the pareto-efficiency of living donation in saving a patient and decreasing the organ shortage), should we allow non-directed (altruistic) donors to designate their donation to members of a specific race, ethnicity, religion, or gender? Does it matter whether the donor's motives are pernicious or discriminatory? A case in Florida exemplified this problem when the family of a Ku Klux Klan member agreed to donate his organs only to white recipients. Although this case involves deceased-donor transplantation, the same logic applies to living donors. Allowing altruistic donors to donate to groups, not individuals, on the basis of race, sex, religion, national origin, or other similar characteristics undermines fairness in the system, since it systematically disadvantages groups of people who may have been waiting longer and are closer to death. As a matter of policy and law, the Florida legislature banned directed donation to persons belonging to specific groups (Ankeny, 2001)

as does the United Network on Organ Sharing (UNOS) (UNOS, 1999). As a matter of justice, even if both parties, the recipient and donor, are informed of all consequences and enter into this arrangement voluntarily, we may still have grounds to be concerned with the transaction. The reason is that for an action to be just, all affected parties must voluntarily enter into the agreement.

Using his example, Nozick in passing defends his position by arguing that third parties maintain their legitimate shares, and as such are not harmed by the transfer of money between fans and Wilt Chamberlain. However, as Cohen has already explained, this could harm third parties by changing their effective share or capability, since the value of their share depends not only on what they have, but on its value relative to what others have. In the case of transplantation, allowing donations that the many people find repugnant, such as discriminatory non-directed donations based on race, ethnicity, gender, or religion, would cause many people to cease their participation in the transplant system. This may harm the legitimate shares of many more people by reducing the total supply of donors by more than the number that would be gained if non-directed donors were allowed to donate for any reason. Furthermore, by undermining fairness and equity in the transplant system, the effective shares of people (the majority) who desire such a system would be significantly hurt. It is worth noting that limiting the scope of the entitlement principle in determination of holdings, for example using taxation, is consistent with using an egalitarian principle to decide the major distribution of goods to maintain certain social norms.¹⁴

¹⁴ It is worth noting that many fundamental views about justice suggest that discrimination is wrong, in particular if it infringes on the rights of third parties. In that LDKT requires use of hospitals that accept public funds and are meant to serve the public, they are subject to public accommodation. This is also true of the national transplant waiting list, which is regulated and run by UNOS. Allowing discriminatory treatment (such as donation based on race, gender, religion, or national origin) would harm third parties by tainting the institutions. Importantly, there might not be a basis for such an objection were LDKTs carried out privately in hospitals or centers that did not accept public money and were not associated with the national organ

The particular nature of living donation maybe also set it apart from other transactions. While should clearly support upholding donor autonomy and protecting individuals from coercion in deciding whether or not to donate, we may, however, have grounds to restrict the way the gift is given and the scope of their gift, more than we would if the gift did not involve medical intervention. For example, to ensure that donation is done safely without causing undue harm to the donor or the patient, we may restrict the timing, and location, even ultimately whether the procedure can be done. Furthermore, given that both parties, the donor and recipient, cannot transact alone but need an agent (medical team) to complete the transaction, the rights and liberties of that entity must also be taken into account. For example, in medicine, although there is a constitutional right of patients to refuse even life-saving treatment, this however, does not imply that patients can impose the right to hasten the end of their life on the medical team and demand life-ending treatment. Were a person wanting to donate two kidneys or a single kidney without being sufficiently health, medical professionals would not oblige, because this would contradict their professional (and maybe personal) code of ethics. In the living donor transplant transaction, we must take into account the liberties of others: surgeons, nurses, the hospital, and others must be involved. (Hanto, 2007; Kluge, 1989). These people and organizations may object to taking part in a transaction that goes against their code of ethics, for example discriminatory donations.

3.5.2 Considering an Egalitarian Objection

transplant system. In this case, however repugnant, the transaction might be viewed as any other private donation, which can be given for any reason, discriminatory or not.

In the case of directed donation of a person to a relative or friend, this has always been allowed and has not been seen as undermining fairness in the organ allocation system. Even under egalitarian theories of distributive justice, some variation in the distribution of goods is permissible. Due to grave shortage of kidneys and concurrent advances in surgical and immunological therapies, LDKT now accounts for a growing fraction of kidney transplants in the United States, and will likely surpass the number of deceased-donor kidneys in coming years. Unlike methods for ensuring equity in deceased donor allocation, where criteria can be publicly debated and organs can be shifted from one patient to another based on changes in the organ allocation scheme, LDKT faces a unique set of challenges. LDKT involves directed donations, and as a result, organs cannot be arbitrarily shifted between patients in order to promote fairness, as they can with deceased donor organs. Directed donation is seen as a method to increase supply, since people are able to donate to their loved ones, directly benefiting both the recipient and the donor. Even in paired exchanges, whereby donor-recipient pairs who are incompatible matches (due to different blood types, for example), both donor and recipient are thought to benefit directly from the procedure. The potential benefits from directed donation, for the donor- the chance to keep a loved one alive and off dialysis- create incentives for people to donate without which they may not have contributed at all. The increase in supply benefits not only recipients of LDKTs, but also those waiting for deceased-donors since arguably recipients of LDKTs would be competing for the same deceased-donor organs. Thus, directed donation is pareto-improving and consequently, there is some justification for allowing this even if disparity results. Still, while it is clear that programs encouraging LDKT increase the overall supply of donors, they also exacerbate disparities.

One way to eliminate disparities in LDKT would be to require that all potential living donors donate to a public pool, whereby organs would subsequently be allocated using the established algorithm. While this approach would likely enhance equity, it amounts to a ‘leveling down’, where the supply of organs donated from living donors would likely plummet and organ scarcity would increase (Parfit, 1997).^{15, 16} While the recipient would still benefit from non-directed or anonymous living donation, the benefit to the donor would be substantially diminished, as would incentives for donation. If we made living donation similar to deceased donation in this way, we would recreate the diminished supply problem of deceased donation, because methods of forcing people to contribute will be unacceptable to those wanting to participate. Leveling down defeats attempts at achieving fairness, since no one is made better off by decreasing the overall supply of organs, and the worst-off are made worse off by increasing their waiting times and decreasing their likelihood of receiving a transplant, despite the more equal distribution of organs overall.

3.6 Policy Implications

Do established theories of distributive justice shed light on how to achieve justice or equity in organ allocation? In the previous sections, we have demonstrated that existing disparities in LDKT can be considered unjust in that they are partly influenced by unjust

¹⁵ The exception to this would be altruistic donors who donate in a non-directed way either to paired-exchange networks or to the national waiting list.

¹⁶ It is worth noting the reference to leveling down in the case has similarities, but also important distinctions from Parfit’s example of blinding sighted people for the sake of increasing equity. In Parfit’s example, blinding sighted people who are not in need creates a situation where needs are more equal, but clearly no one would approve of such an action because it does not result in any gain. In the case of restricting LDKT, the reduced supply of organs due to fewer LDKTs would result in higher mortality because we would fail to save people who would have lived had they received a LDKT. Furthermore, in this case, not only would the identified recipient be saved, but the entire population of patients in need of transplants would be better off because for each living donor kidney the waitlist is reduced by one. In this case, all patients benefit and realize some gains from LDKT, therefore restricting LDKT would lead to a leveling down of benefit.

social forces, operating through social network mechanisms. Theories of distributive justice, however, do not provide policy prescriptions, as they mostly focus on ideal society or do not demonstrate how to weigh one consideration against another. In this section, we consider a range of policy options and their justifications.

Assuming that we want more people to be made healthy and thereby avoid leveling down, is there a way to protect the fair opportunity range and equal access to treatment? A spectrum of policy options are available that would try to accommodate, in part, for Black's systemic disadvantages in LDKT. The mildest of these would entail improving consistency and standardization in education about LDKT. Minority and low-income populations are less knowledgeable and receive less education about transplant than other groups (van Ryn & Fu, 2003). Two randomized controlled trials have studied whether improved dialysis center LDKT education increases pursuit of transplant and LDKT. Both have found that education about LDKT was associated with greater willingness to discuss LDKT with their social networks and to pursue an evaluation (Pradel, Suwannaprom, Mullins, Sadler, & Bartlett, 2008). In particular, African-American patients receiving LDKT education were significantly more likely than their Caucasian counterparts to make a list of potential donors and to discuss LDKT with others.

Given the severity of LDKT disparities, simply providing consistent and equal education about LDKT may not be enough to rectify the gap. Increased clinical and financial resources for vulnerable patients and donors may better serve to compensate African-American patients for their network related disadvantage. Several transplant centers have increased LDKT rates by offering formal family education programs and targeting African-Americans (Foster et al., 2002). A randomized controlled trial of home-based educational interventions demonstrated that significantly more patients in the home-based condition,

particularly African-Americans, had living donor inquiries, evaluations, and LDKTs (Rodrigue, Cornell, Kaplan, & Howard, 2008b; Rodrigue, Cornell, Lin, Kaplan, & Howard, 2007). This program allowed more patients and their support networks to learn about LDKT without taking time off work to go to the transplant center and enabled interested potential living donors to volunteer without requiring kidney recipients to ask directly.

Financial compensation may also help to mitigate some of the gap. Some federal and state initiatives exist to provide compensation for living donors. In addition, the National Living Donor Assistance Center (NLDAC) was established in 2007 to assist individuals with out-of-pocket expenses associated with living donation. For potential living donors who meet specific financial eligibility criteria, the NLDAC provides up to \$6000 in reimbursement for the costs of donor evaluation, surgery, and follow-up, including hotel, travel and meal expenses. Currently, over 100 transplant centers have filed NLDAC applications, with over 200 potential living donors receiving funds (Waterman, Rodrigue, Purnell, Ladin, & Boulware, 2010). With 40% of applicants reporting that they would be unable to afford to donate without NLDAC financial support and African-Americans disproportionately in need of financial assistance for LDKT, this is an important initiative for overcoming financial disincentives to living donation. Additional benefits such as guaranteed health insurance following donation, and other incentives such as assistance with childcare or household needs may also serve to decrease disincentives to LDKT.

Finally, given that DDKT and LDKT comprise all available treatment options for ESRD patients, the most direct way to provide an advantage for blacks would be to provide them with higher priority on the waiting list for DDKT based on their lower chances of obtaining a LDKT. Given their low chances of obtaining a LDKT, and given that DDKT and LDKT are perfect substitutes, providing them special additional priority to compensate

for the fraction of their disadvantage caused by unjust social forces seems reasonable. However, it remains difficult to estimate the fraction of their disadvantage that stems from social injustice, versus the effects of poor but random endowments. Still, our inability to empirically deduce what fraction to account for should not constrain our efforts to restore fairness and equity to organ transplantation. In many respects, African-Americans are disadvantaged under the current system

It is important to note that any change to the allocation algorithm will shift resources along a particular margin, and inevitably, there will be some in any allocation scheme who will suffer and may die while waiting for an organ. There is a limited supply of organs, so any change to the status quo will require one person to wait longer if another is prioritized once their social network is taken into account. The question then becomes, does the person who would have received a kidney under the prior (current) allocation algorithm have a legitimate complaint against this new arrangement? We argue that the complaint, although clearly understandable, is without merit because the allocation has been improved to distribute organs more fairly across people. We have strong reasons to believe that treating people fairly requires accounting for all the complex sources of disadvantage that they face and trying to equalize their prospects after accounting for those factors. We demonstrated that many overarching principles of distributive justice, including strict egalitarian, luck egalitarian, the Difference Principle, and the capabilities approach all support accounting for disparities associated with social networks. Thus, although our intuitions and current practice suggest that we focus only on individual characteristics, a broader view of the individual that takes into account the advantages (or disadvantages) conferred by their social network is a more just approach.

3.7 Conclusion

Because public perceptions of justice and fairness in organ allocation are central to the continued success of a national organ sharing system, ensuring equality and fairness in organ allocation is of central importance. Existing disparities, especially the uneven distribution of LDKTs, pose a threat to fairness in organ transplantation because they suggest that life chances for ESRD patients may be based on ‘irrelevant traits’. For this reason, disparities in LDKT are as morally concerning as disparities in DDKT. Still, our intuitions about regulating a pool of organs donated in a non-directed fashion are different from our intuitions about fairness in circumstances where people donate directly to others. Our intuitions about rectifying disparities in LDKT may differ from our strong intuitions to correct for disparities in DDKT due to the belief that LDKT is a matter of personal choice.

A patient’s ability to successfully undergo LDKT is highly dependent on the health and willingness of their social network to proceed with donation. This is not merely a voluntary interaction, but rather an interaction that is significantly influenced by endowments and personal choice. Importantly, the endowment component is not randomly distributed in the population, but is shaped by social determinants. This endowment (or poor brute luck) disproportionately impedes the chances of blacks to find a suitable donor within their network. White patients are far more likely than blacks to have the option of both living and deceased donor transplantation, while blacks may have only the option to wait for a deceased donor organ. Increasing reliance on LDKT suggests that those with access to living donors are far more likely to receive a life-saving transplant.

Do established theories of justice clarify whether disparities in LDKT resulting from differences in social networks are morally relevant? Many theories of distributive justice,

most notably Rawls's Justice as Fairness, anchor the basis upon which a person is entitled to benefits and shed light on the just distribution of resources. The Difference Principle allows for inequalities so long as they make the least advantaged as well off as possible compared to alternatives (Rawls, 1971). In light of this principle, we must consider whether allowing disparities in LDKT improves or harms the worst off. In some ways, allowing LDKT even replete with inequalities is beneficial. Since organ demand and supply is a closed system, each person who receives a LDKT shortens (or at least does not lengthen) the waitlist by one unit. As a result, black and white patients waiting for a DDKT benefit from others pursuing LDKT. In this way, LDKT is pareto-optimal, as it provides access to organs not otherwise available making no one worse off and some better off than they would otherwise be. Still, allowing the system to proceed as is exacerbates the gap in access to treatment of the most vulnerable group relative to the least vulnerable and intensifies social inequality. In this sense, allowing inequalities in LDKT worsens the relative position of the most vulnerable by widening the gap between them and the best off¹⁷.

Are there ethical grounds for equalizing access to treatment? Are whites entitled to a greater chance of survival because they are linked to more potential donors? Rawls implores us to recognize people do not deserve the benefits owing to their abilities. Instead, justice requires that we consider talents as the result of a random endowment or genetic lottery. Since we are not deserving of our talents (nor do we deserve to win a lottery), Rawls argues that these talents should be considered collectively as a common asset. Much in the same way, social networks can be considered to be in large part, an endowment, (or win of the genetic and social lottery) whose benefit no single individual is deserving of. Instead, these "talents" ought to be considered communally in a national organ allocation system among

¹⁷ It is worth noting that some applications of the Difference Principle will still increase relative gaps since it is about absolute gains to the worst off being as great as possible not about ratios.

those in need of an organ. It is worth noting that even detractors who disagree with Rawls (as Nozick does) that our talents ought to be considered a common asset, agree that an arbitrary distribution of particular talents or traits does not mean that one deserves the benefits of these talents. At the extreme, Nozick argues that the lack of desert only counters individual desert claims, but does not demonstrate why the larger society should be seen as the legitimate repository of individuals' (undeserved) talents. Whether or not one supports Nozick's objection in general, in the unique case of LDKT, access to treatment for patients in need of a life-saving transplant are de facto part of a common pool. Insofar as one is not necessarily deserving of the benefits of their social network, there may be arguments for redistributing the benefits across the population in need. There are, of course, practical limitations to sharing living-donor kidneys communally. Still, there are strong normative grounds to support policies that would help redistribute the benefits of LDKT while not disincentivizing the practice.

The need for fairness in organ transplantation stems from the broader social responsibility of ensuring that all individuals are treated fairly, particularly in the healthcare system. Although this does not implicitly guarantee equality in life chances, it requires that if society has contributed to differential access to LDKT by restricting the ability of certain vulnerable groups to find donors within their social network, then society has the responsibility to correct for that inequality and ensure fair access to treatment for all patients with renal failure. Similar to efforts to adjust for disadvantage associated with socioeconomic status (a characteristic influenced by both endowments and personal choice) on the grounds that is a characteristics that unfairly biases patient's abilities to seek and receive care, so too should the influence of social networks be taken into account in fair resource allocation.

A spectrum of policy options exist, ranging from doing little more than ensuring that

black and white patients are informed equally about their treatment options to compensating black patients who cannot pursue LDKT by providing them a small advantage in the deceased-donor allocation algorithm. Intermediate options include providing patient navigators to Black patients to help through the evaluation process and to facilitate discussions with network members, and additional financial and social supports to assist with overcome the greater burden related to donation. Although the evidence demonstrates that social forces unjustly bias the chances of black patients with ESRD, science cannot yet estimate the precise fraction of the gap that is a result of social determinants. However, the absence of a precise estimate does not negate the need for corrective action. The evidence demonstrates that there is sufficient need for intervention based on the harmful effects of past discrimination and exploitation of Blacks, and a need to equality of opportunity and fairness in medical institutions.

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